

MENTAL CAPACITY REPORT: HEALTH, WELFARE AND DEPRIVATION OF LIBERTY

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Welcome to the June 2020 Mental Capacity Report. Highlights this month include:

- (1) In the Health, Welfare and Deprivation of Liberty Report: the Court of Appeal presses the reset button in relation to capacity and sexual relations, and three difficult medical treatment decisions;
- (2) In the Property and Affairs Report: the impact of grief on testamentary capacity;
- (3) In the Practice and Procedure Report: a remote hearings update, and a pragmatic solution to questions of litigation capacity arising during the course of a case;
- (4) In the Wider Context Report: DoLS and the obligations of the state under Article 2 ECHR, the Parole Board and impaired capacity, and recent relevant case-law from the European Court of Human Rights;
- (5) In the Scotland Report: the interim report of the Scott Review critiqued.

You can find our past issues, our case summaries, and more on our dedicated sub-site here. We have taken a deliberate decision not to cover COVID-19 related matters which might have a tangential impact upon mental capacity in the Report, not least because the picture continues to change relatively rapidly. Chambers has created a dedicated COVID-19 page with resources, seminars, and more, here; Alex maintains a resources page for MCA and COVID-19 here.

If you want more information on the Convention on the Rights of Persons with Disabilities, which we frequently refer to in this Report, we suggest you go to the <u>Small Places</u> website run by Lucy Series of Cardiff University.

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The picture at the top, "Colourful," is by Geoffrey Files, a young man with autism. We are very grateful to him and his family for permission to use his artwork.

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The Court of Appeal, decision-making and sex: have we been getting it all wrong?

A Local Authority v JB [2020] EWCA Civ 735 (Court of Appeal (Sir Andrew McFarlane P, Baker and Singh LJJ))

Mental capacity - sexual relations

[Note, Tor and Nicola Kohn have recorded a half-hour web conversation summarising and commenting upon this decision, available here].

Summary

The Court of Appeal has made clear that we have been asking the wrong question in relation to sexual relations. The issue arose in the context of proceedings concerning a 36-year-old man with a complex diagnosis of autistic spectrum disorder combined with impaired cognition. The question before the judge at first instance, and in written submissions presented to this court before the hearing, was couched in different terms, namely whether a person, in order to have

capacity to *consent* to such relations, must understand that the other person must consent. The first instance judge, Roberts J, had held the fact that the man in question, JB, could not understand that fact, did not mean that he lacked capacity to consent.

The local authority appealed, and sought to persuade the Court of Appeal that Roberts J had been wrong to exclude this information from the information relevant to the test. The Court of Appeal, however, took a different course, steered by Baker LJ (giving the sole judgment of the court).

Baker LJ started by observing that the issue – of great importance to people with learning disabilities or acquired disorders of the brain or mind – required the court to balance three fundamental principles of public interest.

4. The first is the principle of autonomy. This principle lies the heart of the Mental Capacity Act 2005 and the case law under that Act. It underpins the purpose

of the UN Convention on the Rights of Persons with Disabilities 2006, as defined in article 1:

> "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."

- 5. The second is the principle that vulnerable people in society must be protected. As this court observed in <u>B v A Local Authority</u> [2019] EWCA Civ 913 (at para 35):
 - " ... there is a need to protect individuals and safeguard their interests where their individual qualities or situation place them in a particularly vulnerable situation."

Striking a balance between the first and second principles is often the most important aspect of decisionmaking in the Court of Protection. The Mental Capacity Act Code of Practice expresses this in simple terms (at para 2.4):

"It is important to balance people's right to make a decision with their right to safety and protection when they can't make decisions to protect themselves."

6. There is, however, a third principle that arises in this case. The Mental Capacity Act and the Court of Protection do not exist in a vacuum. They are part of a wider system of law and justice. Sexual relations between two people can only take place with the full and ongoing consent of both parties. This principle has acquired greater recognition in

recent years within society at large and within the justice system. The greater recognition has occurred principally in the criminal and family courts, but it must extend across the whole justice system. The Court of Protection is concerned first and foremost with the individual who is the subject of proceedings, "P". But as part of the wider system for the administration of justice, it must adhere to general principles of law. Furthermore, as a public authority, the Court of Protection has an obligation under s.6 of the Human Rights Act 1998 not to act in a way which is incompatible with a right under the European Convention of Human Rights, as set out in Sch.1 to the Act. Within the court, that obligation usually arises when considering the human rights of P. But it also extends to the rights of others.

To resolve the appeal, Baker LJ had to consider both the Act and the development of the case-law. As he noted, there is only reference to sexual relations in s.27(1) of the MCA which provides that nothing in the Act permits a decision to be made on behalf of a person with regard to a number of matters listed in the subsection including "consenting to have sexual relations." He then conducted a very extensive review of the "somewhat confusing" (paragraph 24) case-law, which will no doubt be pored over by those who have been involved (whether directly or indirectly) in the messy evolution of how the courts have grappled with capacity and sexual relations.

Having set out the rival submissions of the local authority as appellant and the Official Solicitor on behalf of JB, Baker LJ then turned (at paragraph 91) to his analysis of the position. He started by recalling the decision-specificity of the

test under the MCA 2005 which means that the ""'information relevant to the decision" depends first and foremost on the decision in question" (paragraph 91). As he then noted:

92. The analysis of capacity with regard to sexual relations in the case law has hitherto been framed almost exclusively in terms of the capacity to consent to sexual relations. But as this case illustrates, giving consent to sexual relations is only part of the decisionmaking process. The fundamental decision is whether to engage in sexual relations. The focus on the capacity to consent derives, in part, from the judgments delivered by Munby J prior to the implementation of the MCA, which unsurprisingly influenced the analysis in subsequent cases after the Act came into force. In addition, as pointed out above, the only reference to sexual relations in the MCA is in s.27 where the list of "excluded decisions" which cannot be made on behalf of a person lacking capacity includes "consenting to have sexual relations". But the list in s.27 does not purport to be a comprehensive list of the decisions in respect of which issues as to capacity will arise.

As Baker LJ noted, the earliest caselaw decided by Munby J had framed the analysis by reference both to the question whether someone has the capacity to consent to sexual relations and also by reference to the question whether someone has the ability to choose whether or not to engage in sexual activity. However, in subsequent cases, the focus had been on the first question to the exclusion of the second. As Baker LJ noted:

92. [...] The word "consent" implies agreeing to sexual relations proposed by

someone else. But in the present case, it is JB who wishes to initiate sexual relations with women. The capacity in issue in the present case is therefore JB's capacity to decide to engage in sexual relations.

Importantly, Baker LJ did not just limit himself to JB's specific situation, but rather emphasised that "[i]n my judgment, this is how the question of capacity with regard to sexual relations should normally be assessed in most cases" (paragraph 92).

As Baker LJ then held:

94. When the "decision" is expressed in those terms, it becomes clear that the "information relevant to the decision" inevitably includes the fact that any person with whom P engages in sexual activity must be able to consent to such activity and does in fact consent to it. Sexual relations between human beings are mutually consensual. It is one of the many features that makes us unique. A person who does not understand that sexual relations must only take place when, and only for as long as, the other person is consenting is unable to understand a fundamental part of the information relevant to the decision whether or not to engage in such relations.

The Official Solicitor had argued that, even if the decision was expressed in those terms, the relevant information should not include an understanding of the consensuality of sexual relations. However, Baker LJ held that none of the reasons stood up to scrutiny:

95. [...] The inclusion of an understanding of the other person's consent as part of

the relevant information does not, as he asserted, recast the test as "personspecific" but, rather, ensures that the information is firmly anchored to the decision in question, as required by statute and confirmed by this court in the York case. I accept that it is important for the test for capacity with regard to sexual relations to be as simple and straightforward as possible but that cannot justify excluding information which is manifestly relevant to the decision. And if the consensuality of sexual relations is part of the relevant information, it plainly relates to capacity itself rather than the exercise of capacity.

96. Mr Patel understandably relies on earlier judicial observations that sexual activity, and decisions made about such activity, are "largely visceral rather than cerebral, owing more to instinct and emotion than to analysis". But it has never been suggested that decisions are exclusively visceral or instinctive. It is, of course, true that sexual desire is emotional rather than intellectual, but for human beings the decision whether or not to engage in sexual relations obviously includes a cerebral element. It involves thought as well as instinct. And amongst the matters which every person engaging in sexual relations must think about is whether the other person is consenting.

97. Mr Patel also relies on the point made in earlier judgments that the focus of the MCA is different from that of the criminal law. It would, however, be wrong and unprincipled to exclude an understanding of the consensuality of sexual relations from the relevant information on the grounds that non-consensual sexual acts should be dealt with by the criminal justice system. As illustrated by the

background history to this application, which includes an incident of alleged sexual abuse in respect of which the police decided to take no action, the criminal justice system does not necessarily deal with such cases and there may well be good reason for this, because the police and the prosecution authorities have a discretion whether or not to pursue every potentially available criminal charge and exercise that discretion in the public interest. But even if it could be guaranteed that such incidents were dealt with by the criminal courts, to leave such matters to the criminal justice system would be an abdication of the fundamental responsibilities of the Court of Protection, which include the duty to protect P from harm.

Baker LJ returned to the importance of striking a balance between the principle that vulnerable people in society must be protected and the principle of autonomy is often the most important aspect of decision-making in the Court of Protection. However, he did:

98. [...] not accept the argument that including an understanding of the consensuality of sexual relations as part of the information relevant to the decision about the capacity regarding sexual relations amounts to an unwarranted infringement of JB's personal autonomy or of his rights. Insofar as it is a restriction of his autonomy and his rights, it cannot be described as discriminatory because it is a restriction which applies to everybody, regardless of capacity. As social beings, we all accept restrictions on our autonomy that are necessary for the protection of others. No man is an island. This principle is well recognised in the

European Convention on Human Rights. For example, the rights in Article 8 are not absolute and must be balanced against other interests, including the rights of others. Although the Court of Protection's principal responsibility is towards P, it is part of the wider system of justice which exists to protect society as a whole. As I said at the outset of this judgment, the Mental Capacity Act and the Court of Protection do not exist in a vacuum. They are part of a system of law and justice in which it is recognised that sexual relations between two people can only take place with the full and ongoing consent of both parties.

Baker LJ recognised that by recasting the decision as the decision to engage in sexual relations, and by including an understanding of the consensuality of sexual relations as part of the information relevant to the decision, the Court of Appeal was "moving on from the previous case-law" (paragraph 99). However, he made clear:

99. [...] But that is because the issues arising in this case and the arguments presented to us have not been considered by this Court before. In my judgment, however, it is not inconsistent with the earlier authorities of this Court. As recognised by this Court in B v A Local Authority, "what comprises relevant information for determining an individual's capacity to consent to sexual relations has developed and become more comprehensive over time." That development has continued in this case. The Court in IM v LM stressed that "the notional process of using and weighing information attributed to the protected person should not involve a refined analysis of the sort which does not

typically inform the decision to consent to sexual relations made by a person of full capacity". But as already stated, the information which а capacitous individual must take into account in deciding whether to engage in sexual relations includes whether or not the other person is consenting. My decision in this case is therefore not inconsistent with earlier decisions of this Court. As for the decisions at first instance. I respectfully disagree with the contrary observations of Parker J in London Borough of Southwark v KA and Mostyn J in D Borough Council v B.

In summary, therefore:

- 100. [...], when considering whether, as a result of an impairment of, or disturbance in the functioning of, the mind or brain, a person is unable to understand, retain, or use or weigh information relevant to a decision whether to engage in sexual relations, the information relevant to the decision may include the following:
- (1) the sexual nature and character of the act of sexual intercourse, including the mechanics of the act;
- (2) the fact that the other person must have the capacity to consent to the sexual activity and must in fact consent before and throughout the sexual activity;
- (3) the fact that P can say yes or no to having sexual relations and is able to decide whether to give or withhold consent;
- (4) that a reasonably foreseeable consequence of sexual intercourse between a man and woman is that the woman will become pregnant;

(5) that there are health risks involved, particularly the acquisition of sexually transmitted and transmissible infections, and that the risk of sexually transmitted infection can be reduced by the taking of precautions such as the use of a condom.

Baker LJ noted that there remained the question whether the information relevant to the decision whether to engage in sexual relations must always include all of the matters identified in the previous paragraph. Whilst he recognised that this was a matter of considerable importance, it did not arise on the appeal before the court, and the summary of the case-law that he had set out "illustrates that on several occasions judicial obiter dicta in this difficult area of the law have been initially followed by other judges, only to be rejected in later cases after hearing further argument. For that reason, it would be prudent for this Court to refrain from commenting until it has an opportunity to hear full argument on the point in a case where the issue arises on the appeal" (paragraph 103).

On the facts of the case before the court, and whilst commending the judge's "strong commitment to the principle of autonomy, and the right of disabled people to enjoy life's experiences to the full," Baker LJ found "with considerable regret" that he had to part company from her:

106. First, I do not consider it appropriate to view these issues through "the prism of the criminal law". In fairness to the judge, I think she was understandably led into this approach by dicta in previous reported cases and by submissions given to her by counsel, who in turn were influenced by the earlier cases. But in my view it is unnecessary and inappropriate to consider whether "a full and complete

understanding of consent in terms recognised by the criminal law" (my emphasis) is an essential component of capacity to have sexual relations. What is needed, in my view, is an understanding that you should only have sex with someone who is able to consent and gives and maintains consent throughout. The protection given by such a requirement is not confined to the criminal legal consequences. It protects both participants from serious harm.

although 107. Secondly, some capacitous people might struggle to articulate the precise terms of the criminal law in this regard, I do not agree that capacitous people have difficulty understanding that you should only have sex with someone who is able to consent and who gives and maintains consent. I respectfully disagree with the judge that this is "a refined or nuanced analysis which would not typically inform any decision to consent to such relations made by a fully capacitous individual". Nor is it "a burden which a capacitous individual may not share and may well be unlikely to discharge". It is something which any person engaging in sexual relations has to consider at all times. This is not altered by the fact that some capacitous people choose to ignore the absence of the other person's consent and proceed with sexual activity anyway (thus probably committing a criminal offence such as sexual assault or even rape).

107. Thirdly, I do not think it right to reject the requirement of an understanding as to the necessity of mutual consent to sex on the grounds that there are "mistakes which all human beings can, and do, making the course of a lifetime". There may be occasions, I suppose, where

someone genuinely makes a mistake about whether their sexual partner is giving or maintaining consent. But that circumstance, if it ever arises, is very different from the situation where one person does not understand that the other person has to give and maintain consent

The Court of Appeal therefore set aside the declaration that JB had capacity to consent to sexual relations. However, whilst it could have made its own declaration, Baker LJ held that it was wrong to do on the specific facts of the case, and, in particular, the way in which the issue had been analysed before Roberts J. He therefore held that the right course was to remit it to her to reconsider in light of the judgment and such further evidence as she would wish to seek. The court therefore remitted the case, making an interim declaration under s.48 of the MCA that there is reason to believe that JB lacks capacity to decide whether to engage in sexual relations.

Comment

This is an extremely significant judgment, and it is very likely that the matter will not stop there (and is likely to be by considered by the Supreme Court together with the case of *Re B*). By both recasting the question in JB's case and suggesting that this is the way in which capacity with regard to sexual relations should normally be assessed in most cases, the Court of Appeal has essentially pressed the reset button on what has become an intensely tangled – and frankly unsatisfactory - series of cases. It responds to the fact that individuals with impaired decisionmaking capacity are not always (as some of the previous cases could be read as suggesting) purely passive recipients of sexual activity initiated by others, but can also be sexual beings

wishing to express themselves by initiating sexual activity.

Alex's view (not one necessarily shared by his fellow editors!) is that a very important consequence of this decision is that - in principle – it opens the way for a court to take the view that it is not bound by s.27 MCA 2005, which provides that nothing in the MCA permits a decision to be made on behalf of a person to consent to having sexual relations. Would it be possible to say a court (and I very specifically say court here, as it would be very challenging for anyone to take steps here without judicial imprimatur) can make a best interests decision behalf of someone to engage in sexual relations? And, if so, would this be the way in which to resolve the pragmatic but (to purists, problematic) compromise hammered out in the TZ cases (decided by Baker himself) to the situation where the person is undoubtedly at risk in some sexual encounters, but not in others? That compromise is to find that the person has capacity to consent to sexual relations but does not have capacity to make decisions as to contact, thereby enabling best interests decisions to be made in relation to contact where it is clear that the contact is for purposes of sex.

Another important consequence is that it clears the way to resolving what was otherwise a very odd potential outcome. By framing the test by reference to consent, it would be possible to find that a person could not consent **solely** because they did not understand that their partner needed to consent. But – as we pointed out in

our <u>note</u> upon the first instance decision¹ – that could mean that a partner who freely initiated sexual activity with them could face criminal consequences even if there was no suggestion that the partner had any impairment in their decision-making. The interaction between the MCA and the Sexual Offences Act 2003 remains complex and difficult, but this judgment may at least have helped clear the path of some of the more tangled undergrowth.

Finally, for a perspective from a social worker, we commend the <u>article</u> in Community Care by Lorraine Currie, Acting Principal Social Worker and professional lead for the MCA at Shropshire County Council.

'True' best interests, advance decisions and the subjective approach

Barnsley Hospitals NHS Foundation Trust v MSP [2020] EWCOP 26 (Hayden J)

Best interests - medical treatment

In this case, Hayden J considered an application, initially made to him as the Out of Hours judge, for determination of the question of whether a Trust should continue to provide ITU support to a 34 year old man, or withdraw treatment other than palliative care. For more than a decade, the man – identified as MSP – had painful and complex abdominal problems. In October 2019, he underwent surgery where an ileostomy was formed (in other words, his small intestine was diverted through an opening in his abdomen). 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 May 2020. The evidence before the court was, as Hayden J recorded, that MSP "utterly loathed life with a stoma."

On 4 February 2020, MSP drafted a carefully crafted 'Advance Directive' (as he called it), which he copied to his parents and to his stepsister. Outside the hospital setting these were the only three people who knew MSP had a The advance decision to refuse stoma. treatment was detailed and comprehensive, and also included (although, technically, as advance statements) making provision for music to be played in the event that he fell into coma and at his funeral (the former reflecting the violent and frightening dreams he had when ventilated on ICU previously in 2013). It included, amongst the treatments that he refused "[t]he formation of a stoma, through an ileostomy, colostomy, urostomy or similar, that is expected to be permanent or with likelihood of reversal of 50% of under". Unfortunately: (1) the advance decision was not witnessed, as required by the provisions of s.25 MCA 2005; and (2) no-one outside those people identified above were aware of it.

In mid-May 2020, MSP returned to hospital with very significant abdominal pain and sepsis. Mr M, who was 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. Unfortunately, and for reasons which were not entirely clear, the advance decision was not brought to the hospital's attention until after Mr M had operated. Crucially, at the time of MSP's admission nobody had any reason to doubt his

¹ Which Alex cannot help but note did question whether the right question was being asked at first instance.

capacity, indeed he did not lack capacity at that stage. There was no doubt that MSP expressed his consent to the stoma being inserted, although when the application came to court, it was clearly a surprise to the two other doctors who gave evidence, and who had known MSP for some time.

The stoma was formed on 27 May 2020, and, in fact, MSP's clinical situation was such that it would have to be irreversible. It is not entirely clear what prompted the application to court, but it appears that it may well have been the bringing to the Trust's attention of the advance decision that MSP had sought to create.

At the point that the application came before Hayden J, MSP was sedated and ventilated in ITU. He was breathing spontaneously with only a small amount of support. In the circumstances, as Hayden J identified (at paragraph 19): "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."

As Hayden J noted at paragraph 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.

Hayden J set out in considerable detail the evidence from MSP's family, in particular his mother, which led him to say (at paragraph 17) that:

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.

Hayden J then reviewed the legal framework, observing that:

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.

Having outlined the relevant authorities, he agreed (at paragraph 33) with the submission on behalf of the Trust that their import was 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.

Hayden J also took the opportunity to reiterate (as he had previously done in NHS Cumbria CCG v Rushton [2018] EWCOP 41) the importance of compliance both with the statutory provisions and the codes of practice when preparing an Advance Decision. As he noted at paragraph 36, "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."

Hayden J then held that:

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.

Hayden J had, though, to evaluate the relevance of the conversation between MSP and the surgeon, Mr M, during the course of which he had consented to the formation of the stoma. He agreed with the submission on behalf of the Trust that 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":

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 agreed Directive'. he 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.

What, then, to do?

44. As Ms Castle [the Official Solicitor] 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.

Hayden J emphasised that it was important to break the issues down analytically, in particular to disentangle the question of whether or not the stoma should have been created from the question of whether it was now in MSP's best interests for ITU treatment to be continued, especially parenteral feeding:

46. [...] 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 [i.e. withdrawal of artificial nutrition and hydration with continued sedation which, ultimately,

will compromise respiration and lead to MSP's death]. 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.

Hayden J, finally, held that the anonymity of MSP should be protected for the remainder of his life and for a period of three months following his death, noting, in particular, the extent to which MSP wanted to conceal his stoma from the world.

Comment

Hayden J was, rightly, at pains to emphasise that the case was not about the creation of stomas per se. As he noted (at paragraph 7): "[m]any 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.

The case is also of note for the way in which Hayden J had to navigate:

- (1) the mismatch between the consent to the procedure and the purported advance decision; and
- (2) the fact that as a matter of law he could not take a decision on behalf of MSP, now, to refuse continued life-saving treatment **simply** so as to seek to turn back time and undo what would have been MSP's very likely refusal of treatment at the point of the critical conversation with the surgeon.

The way in which Hayden J undertook this exercise could properly be described as respecting MSP's rights, will and preferences: i.e. complying with the provisions of Article 12 of the Convention on the Rights of Persons with Disabilities.

That having been said, one matter that the judgment does not address in terms is the fact that – on the face of it – it does not appear that MSP was clinically in a situation in which it would have been impossible to rouse him so as to be able to ask him what he wanted. It is unlikely that this was not considered by those present, but it is perhaps to be regretted that this was not addressed expressly, not least so that Hayden J could have answered the question of whether the requirement in s.1(3) "all practicable steps" to support the person to take their own decision before having recourse to best interests decision-making has to be judged by reference to what the person themselves would have

wished. In other words, would it have been legitimate for the court to consider as part of its consideration of MSP's decision-making capacity whether MSP would have wished to have been brought out of sedation to be confronted with the true position?

It is, separately, perhaps of some importance to understand what this case has to do with advance decisions Even had it been procedurally compliant by being witnessed, it would not have been applicable at the point of the discussion with Mr M, as MSP had capacity at that point. It is also not entirely obvious that it would have meant (for instance) that clinically assisted nutrition and hydration would have to have been stopped when the Trust became aware of it, because it is not, on its face, obvious that it covered precisely the circumstances in which MSP now found himself. Rather, the advance decision in this case served as very powerful evidence of MSP's wishes and feelings as regards the sort of treatment to which the court was now being asked to consent to or refuse on his behalf. The case therefore reinforces the importance that advance decisions - wherever possible - contain statements which enable decision-makers to understand the values and priorities of the person concerned. An example of how to create such an advance decision can be found here. For more on the mechanics of advance decisions, see Alex's (updated) discussion paper here.

Finally, on a procedural point, Hayden J took the opportunity to note, and (rightly) to credit the Official Solicitor with being able to re-establish an out of hours service — it had been a very troubling state of affairs for several years that in

very urgent medical treatment applications brought out of hours, the court was frequently not in a position to be able to look to the Official Solicitor to be able to represent P.

Navigating the silos

A Local Authority v AW [2020] EWCOP 24 (Cobb J)

Mental capacity – assessing capacity – contact – residence – sexual relations

Summary

Characteristically, Cobb J delineated the issue to be decided in this case at the very outset:

This judgment does not establish any great or new point of legal principle. It sets out my reasoning in reaching conclusions in a case which has the characteristics of many which come before the Court of Protection: namely, where the subject of the application is believed to have capacity in making decisions in relation to certain aspects of their life, but not in others; where there are, in such cases, inevitably 'grey areas' in between. It recognises the importance of treating each capacity issue as decision-specific and time-specific, as the judicial guidance in PC v City of York Council [2014] 2 WLR 1^[1] and B v A Local Authority [2019] EWCA Civ 913; [2019] 3 WLR 685^[2] makes clear. Where there are true 'grev areas', it illustrates the value of giving the parties and the court the chance, while at all times maintaining an eye on the key objectives laid out in the Court of Protection Rules 2017, to examine the evidence forensically, test the assessments and expert views, and achieve, where possible, a degree of clarity in the best interests of the subject. In cases such as this, the "right of every individual to dignity and selfdetermination" compete hard with the "need to protect individuals and safeguard their interests where their individual qualities or situation place them in a particularly vulnerable situation" (B v A Local Authority at [35]).

The case concerned AW, a 35-year old man with a diagnosis of mild learning disability and autistic spectrum disorder. He had lived at a residential care placement, Windmill House, for 7 years. He was described as having "many skills", and was assessed as someone who:

... can appear very able and without further examination would commonly appear more able than he is. This is due to his keenness to engage with others, relatively good self-presentation skills, verbal skills, and ability to learn phrases. He is a very likeable man. It is easy to underestimate his vulnerability and difficulty to apply abstract concepts of safety in relationships due to his autism.

As an adult, AW pursued gay relationships, spending much time and deriving pleasure from accessing gay websites, gay chat rooms and dating sites; he enjoyed watching others performing sexual acts in the chat rooms, which he found sexually arousing. While his mother was accepting of this when he was living at home, it nonetheless raised concerns for her and those caring for him, particularly given his social vulnerability. Those concerns became all too real in 2009 when AW was seriously sexually assaulted by a man who he had met on the internet; the police became involved, although no prosecution followed. A further safeguarding referral followed in 2012, when he moved in with another man who he had met on the internet.

More recently he had engaged in inappropriate behaviour with a minor, which unsurprisingly led to police involvement. Numerous incidents were detailed before the court in which AW had placed himself at very considerable risk in the company of men whom he had met through dating sites on the internet. When these relationships had run into difficulties, or had soured (as inevitably had been the case), AW often responded aggressively, and verbally and physically assaulted those around him (including his mother), sometimes indiscriminately. He had also run up significant debt through his excessive phone and internet use.

When AW moved to Windmill House in 2013, and routinely since, his care needs had been assessed; he was considered to be unable without support and supervision to maintain a habitable home environment, unable to manage and maintain nutrition, maintain his personal hygiene, be appropriately clothed, develop and maintain family or personal relationships, make use of necessary facilities or services in the community. Such was his level of need that he had forty hours of one-to-one support per week, including specifically times when he was accessing the community. He was said generally to be very happy at Windmill Lodge, though because he spent many hours at night on the internet and on his phone, he tended to sleep all day, missing activities; this had caused him to become somewhat socially isolated.

AW's access to, and use of, the internet and social media was limited and restricted by the care staff at the care home. He was subject to 1:1 supervision when accessing the internet (which was permitted once per day) and at all other times, he had not had access to internet

enabled devices. The Local Authority maintained that, due to the risks associated with AW's behaviour when using the internet, it was in his best interests to be supervised to access websites, including dating websites.

The Local Authority accepted that AW was able to engage with men on dating sites and should he wish to take the step of meeting someone in person, then (subject to the restrictions in place as a result of the COVID-19 pandemic) the care plan would be followed, and that individual would be risk assessed. Subject to the outcome of any such assessment, arrangements for direct contact would be made. Care staff had accompanied AW to clubs and events which would enable him to engage with other men. They wanted to continue to discuss his need for a relationship with him in an open manner, whilst at the same balancing his needs for safety and protection from exploitation.

In late 2019 (and until the end of February 2020), AW had become fixated on a man who lived at a separate residential placement. At the time of his assessment by the psychiatrist directed to report to the court, Dr Rippon, AW was intent on moving to the placement to take that relationship further. However, subsequently, AW made clear that, as the man no longer wanted to progress the relationship, he did not want to move.

In February 2020, Cobb J had – by agreement – made declarations that AW lacked capacity to conduct the proceedings; to make decisions about contact with others; to use social media and the internet; to make decisions about disclosure of personal information to others; but that he **had** capacity to consent to sexual relations. As Cobb J noted:

This suite of conclusions reflects a potential anomaly (as Hayden J reflected in Manchester City Council Legal Services v LC & Anor [2018] EWCOP 30 at [10]) namely the "decision making facility to embark on sexual relations whilst, at the same time, he is not able to judge with whom it is safe to have those relations".

As he noted, later in the judgment, the fact that AW had capacity to consent to, and enter into, sexual relations:

42. [...] creates potentially difficult challenges for the Local Authority, and the court, in balancing the positive obligations to ensure that AW is supported in having a sexual relationship should he wish to do so, while also ensuring, as far as possible, that he is kept safe from harm.

43. A detailed 'best interests' care package has been drawn up which defines the support which AW will receive so that he can safely meet in person (when able to do so) those 'friends' who he has 'met' online; this care package seeks to strike a balance between offering AW protection, while affording him privacy and a degree of autonomy. The Local Authority clearly understands that it is not its role to vet AW's partners, or to deny him time with proposed sexual partners simply because the local authority considers them to be unsuitable. A person-specific contact assessment will be undertaken to establish whether AW has the capacity to have contact with an individual, and a specific support plan drawn up as appropriate, in line with the decision in A Local Authority v TZ [2014] EWHC 973 (COP). The staff at Windmill House have been prepared to accommodate AW in

entertaining visitors provided that his request has been properly risk assessed; provision has also been made in the care plan for an overnight stay with a partner albeit away from Windmill House.

At the hearing in February 2020, Cobb J adjourned consideration of the issues of whether AW lacked capacity to make decisions regarding (a) where to reside and (b) his care and support arrangements, as these were to a greater or lesser extent contentious.

At the time of the hearing in May 2020, given that AW did not wish to leave Windmill House, the issue of capacity to decide upon residence had become academic, but Cobb J agreed to determine the issue on the basis that this would avoid another return to court in the future if AW met another man and wished to move again. Cobb J identified that:

45. [...] On these facts, I have particularly focused on the difficulties which AW has in considering "the difference between living somewhere and visiting it", and "what sort of care he would receive in each placement in broad terms" (see [32] above). Dr. Rippon is of the view that while AW has some understanding of such information, he is not able to use or weigh it (he did not understand "the implications", "the consequences of moving"), and that his decision-making about residence is and has been wholly driven by other factors, most notably at the time of her assessment, his fixation to pursue a relationship with Trevor.

46. Nor, in Dr. Rippon's view, was AW able to understand, use or weigh, with what areas of his life he needs support, and what sort of support he needs ("he did not think he needed [support staff] twenty-

four hours a day, although could not describe what level of staffing he believed he would require"; he "struggled to answer open questions about the support he requires" [32] above). AW was unable, on assessment, to understand that those who would be providing him with support at Thornley House (should he move there) would not be familiar with him, and he was unable to predict what would happen if he did not have any support or he refused it. It is noted that is a degree of overlap in the information relevant to the two questions, and I am conscious that they should not be considered in separate 'silos' (Re B).

47. I accept the evidence of Dr. Rippon that AW struggles to understand abstracts, and this is secondary to his autism disorder. In relation to both residence and care, this particularly means that AW is unable to see the risks attendant in any situation; he can see the positives but not the negatives. I am further satisfied, from what I have read and heard, that no practicable steps can be offered to AW to assist him to change this way of functioning, and assist him to attain capacity.

Importantly, on a proper analysis, and contrary to the position that at one stage had suggested itself:

48. Although the written material may have suggested otherwise, having heard the oral evidence and submissions I have reached the conclusion that this is not a case in which AW fluctuates in his capacity to decide on the issues under consideration. I accept that there is a basic and profound lack of understanding, and that, by reason of the deficits in his executive functioning, he

has a pervasive inability to use or weigh the information. I accept Miss Thomas' that submission his levels understanding and engagement with relevant issues do vary from time to time, but never to a point where it could be said that he is capacitous. When he is engaged, and not distracted by his obsessions, particular care should be taken by those who care for him to permit and encourage him to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him and must (as Miss Thomas accepts: see [36] above) attach particular weight to AW's "past and present wishes and feelings".

Cobb J also held both that AW was deprived of his liberty at Windmill House, and that this was lawful for purposes of Article 5 ECHR.

Interestingly, Cobb J took care to note that:

I am satisfied from all that I have read that AW is becoming adversely affected by the proceedings. He has expressed a wish not to see his solicitor or social worker, and he has had little contact with his advocate. His mother agrees with this, expressing her concern (see [7] above) that the proceedings are causing him to become 'shut down'. It is patently in his interests that the proceedings come to an end, and the orders I shall make shall therefore be final orders.

Comment

Although Cobb J modestly suggested that the judgment did not establish any or new great

of those points arise out of the careful recitation and analysis of the evidence going to capacity, serving as a model of the resolution of a complex - finely-balanced - case. Others arise out of the fact that this is another in a small (but slowly growing) body of case-law relating to executive functioning, described (at paragraph 39) as "the ability to think, act, and solve problems, including the functions of the brain which help us learn new information, remember and retrieve the information we've learned in the past, and use this information to solve problems of everyday life" - crucially, and properly, linked to one of the MCA criterion (in this case, his problems with executive functioning being such as to prevent AW being able to understand the information relevant to residence and care).

legal principle, it is – as Sherlock Holmes would

have said – not without points of interest. Some

Finally, the case now needs to be read in light of the subsequent decision of the Court of Appeal in <u>JB</u> that capacity in the context of sexual relations should be normally, in most cases, be assessed on the basis that the decision is whether the person has capacity to engage in sexual relations not - as Cobb J was loyally considering here 2 - capacity to consent to sexual relations. AW's case is a paradigm case in which, as a person who was not merely a passive recipient, but an actual initiator of sexual activity, it becomes very clear in light of JB that talking about 'consent' was simply asking the wrong question. If this case had been decided after JB, it is likely that the court would (1) have been concerned as to whether AW could process the information that any prospective sexual

though the declaration made was (as was conventional at the time) framed solely as "capacity to consent to sexual relations."

² Although it should perhaps be noted that Cobb J himself, referred at paragraph 42, to AW's capacity to consent to, "and enter into" sexual relations, even

partner had to consent before and throughout the relevant activity; and (2) explored whether it was necessary to undertake the TZ 'workaround' to secure his ability to express himself sexually without putting himself at risk. It could, potentially, have approached the question that, on a proper analysis, AW did not have capacity to decide to engage in sexual relations, and that best interests decisions could be made on his behalf as to when to engage in such relations, taking into account the potential risks that he might be at and might pose in so doing.

Dental treatment and the Court of Protection

United Lincolnshire NHS Foundation Trust v Q [2020] EWCOP 27 (Gwynneth Knowles J)

Best interests - medical treatment

Summary³

Q was 57-year-old woman, with profound and lifelong learning disabilities together with epilepsy. She also had impaired eyesight and was registered blind. She had mobility difficulties which necessitated the use of a wheelchair. Those who cared for her believed her to suffer from some form of autistic spectrum disorder and it is clear that, from time to time, she displayed what was described as extremely challenging behaviour to her carers. She had lived for about 14 years in a supported living placement with two other residents and had 24hour care and supervision. She was highly resistant to changes in the very rigid structure of her daily life and she could reject attempts to provide her with personal care. For many years,

she had resisted any proper or thorough dental hygiene.

Throughout 2018, increasing concerns were expressed about Q's teeth, and about the pain that she appeared to be experiencing. By September 2019, a full dental clearance under general anaesthetic was planned, but on the day of the operation, it was cancelled as Q had a prolonged seizure of around six minutes whilst getting ready to come to the hospital.

Best interests meetings were held on 20 November 2019 and 11 February 2020 and it was agreed by everyone present that it would be in Q's best interests to undergo the proposed dental surgery and to receive intramuscular sedation to facilitate her transfer to and from hospital. Although not clear from the judgment, it appears that it must have been the consideration of sedation which triggered the application to the Court of Protection (there is nothing to indicate why the previous intention to carry out the full dental clearance had not been thought to merit an application).

The NHS Trust made an application to the court for an order and declarations that Q lacked the capacity to make decisions about her dental treatment, in particular, whether she should undergo a full dental clearance under general anaesthetic. It was submitted that it was in her best interests to undergo full dental clearance under general anaesthetic to relieve the pain and discomfort caused by periodontal disease and to receive sedation to facilitate her transfer to hospital to undergo such surgery. The applicant Trust was particularly concerned that the

³ Note, Nicola having been involved in the case, she has not been involved in writing this report.

deterioration in Q's oral health was compromising her health generally, causing her pain, and complicating her enjoyment of food which was identified as being one of her great pleasures in life.

Gywnneth Knowles J identified that there was "a wealth of evidence before the court that Q lacks the capacity to conduct these proceedings and to make decisions about her dental treatment," it being "plainly evident that Q has no ability to understand the most basic of discussions about oral hygiene or dental treatment. She cannot, in my determination, understand, retain, use, or weigh any of the information relevant to the decision whether or not to have such treatment, specifically full dental clearance, or the sedation and transport necessary to carry out such treatment" (paragraph 16).

Turning to best interests, there was clear medical evidence before the court outlining the risks and benefits. On the basis of the evidence before the court, Gwynneth Knowles J considered it reasonable to infer that Q continued to experience dental pain. She noted that the Official Solicitor was:

22 [...] anxious to ascertain whether alternative and less invasive treatment options had been considered by the Trust. On receipt of answers to her questions from Dr A [the associate specialist in oral surgery], the Official Solicitor reassured is that comprehensive assessment of Q's dental health will be carried out once she has been conveyed to hospital and, if there are any teeth which are sound and firm and likely to remain so for a reasonable period, that Dr A will exercise her clinical judgment to decide whether these teeth should be retained rather than extracted. Though as a result of the COVID-19 crisis the Official Solicitor has been unable to instruct an independent expert in special care dentistry, it is accepted by her that the evidence filed in support of Q's dental care plan is comprehensive and thoughtful.

Of some note is that:

22. [...] Again, by reason of the COVID-19 crisis, the Official Solicitor has been unable to visit Q to ascertain her wishes and feelings. She does however accept, having read the minutes of the meeting undertaken by Ms B with Q on 30 April 2020, that Q's ability to communicate is very limited indeed due to her severe learning disability. It is thus difficult to ascertain with any certainty what Q's wishes and feelings are about the proposed dental treatment. I agree.

The plan for the transfer involved the covert administration of ketamine because, it was said:

24. [...] when anxious, Q becomes extremely aggressive, damaging her wheelchair and injuring staff and she is likely to become anxious and distressed if any attempt is made to take her to hospital voluntarily. The administration of ketamine covertly before departure allows for Q to be sedated when travelling to and fro from hospital by ambulance. Two previous occasions, as I have already indicated, to bring Q to hospital have been unsuccessful as no chemical restraint was used. Q became upset and had a prolonged fit. I accept that Q needs to be sedated to be safely transferred to and from the hospital. The use of a sedative administered covertly and safely, as happens with her annual flu

injection, is proportionate and the least restrictive measure in the circumstances of this case.

Gywnneth Knowles J was satisfied, that "standing back and looking at matters in the round":

25. [...] the proposed plan for medical and dental treatment is in Q's best interests. The plan is supported by all those who know Q well including her own sister. Though there is, of course, inherent risk in the administration of a general anaesthetic, the evidence of a consultant neurologist with a special interest in epilepsy indicates that the risk to Q is small and can be appropriately managed.

26. I have also considered that after surgery, Q's recovery is likely to be both painful and upsetting for her because she lacks the understanding to recognise what has happened to her and why it has happened. However, this will be transient discomfort after which she should be able to enjoy her food and derive pleasure from eating without pain. That transient discomfort has also to be balanced against the significant risk of, if untreated, Q experiencing worsening pain where she refuses food, becomes malnourished, and is at risk of developing sepsis. In my view, the course of action proposed by the applicant trust is necessary and the least restrictive possible course in order to carry out the dental treatment that Q urgently needs and has needed for some time on the evidence before me. I am satisfied that it is in her best interests to make the order sought in respect of dental treatment and I approve the contents of the draft order which has been placed before me.

Comment

By the time that matters had come to court, it appears clear that there really was only one outcome that could enable Q's ability to eat without pain and enjoy her food which, as Gynneth Knowles J identified, would vastly improve her quality and enjoyment of life. However, as with so many cases, the judgment is only the tip of the iceberg, and this reader at least is left wondering (1) whether Q had always been as resistant to support with dental hygiene as she had become in later years; (2) if she had, how had she reached her 50s without more serious problems; (3) if she had not, what had changed in her life and/or the way in which those around her supported her to make her more resistant; (4) what triggered the change in thinking from the relevant professionals to make them think that an application to court was now required in circumstances where (it appears) they had previously been content to administer a general anaesthetic to Q and carry out a full dental clearance on the basis of the 'general authority' in s.5 MCA 2005.

Where the buck stops – medical treatment decisions and the Court of Protection

Re GTI [2020] EWCOP 28 (Williams J)

Best interests - medical treatment

Summary

GTI was a 45 year old man, with an established history of schizoaffective disorder. It had been controlled with psychotropic medication and he has lived in supported accommodation in the community. His daily routine included preparing meals, shopping, socialising in the pub, cooking and watching television. However in January

2020, during what appears to have been a paranoid episode, he appears to have stabbed himself in the neck causing significant damage to his recurrent laryngeal nerve. The neurological damage had affected his swallowing reflex and he was now unable to take food or drink orally without significant risks of aspiration, with food and drink passing into the lung. That carried with it the risk of recurrent aspiration pneumonia and physical asphyxia leading to respiratory arrest.

GTI had been taken to hospital after he had stabbed himself, where he had initially agreed to the insertion of a percutaneous endoscopic gastrostomy ('PEG'). However, his position then changed (after he had been detained for assessment under s.2 MHA 1983), and the operation did not go ahead as there were concerns about its legality. He was then transferred to a mental health unit with a nasogastric ('NG') tube in place. He pulled this out within 24-hours of admission and was given leave under s.17 MHA 1983 to go to another (physical health) hospital. Numerous attempts had been made to encourage GTI not to interfere with his total parenteral nutrition ('TPN') lines and to agree to the PEG insertion but without success. He had been able on two occasions to drink water from a tap whilst having a shower and obtained a piece of chocolate. He was now supervised permanently by two mental health staff which is plainly highly intrusive.

GTI did not accept that he was unable to eat or drink normally. These seem to be perhaps two of the significant pleasures in his life but he is unable to accept the risks of aspiration or asphyxia. Since the injury he has been fed either by NG tube or directly into his bloodstream by

TPN but GTI is resistant to these measures which are in any event only ever contemplated as temporary measures. He has removed several NG tubes and TPN lines inserted to feed him.

By the time of the application to the Court of Protection in May 2020, he had lost some 30% of his body weight. Further, his clozapine medication which the evidence suggested had kept his schizoaffective disorder well-controlled has had to be stopped because he had begun to develop agranulocytosis, a well-recognised adverse side effect of clozapine. The development of this side-effect was caused by his deteriorating physical condition associated with the lack of nutrition.

At a clinical decision-making meeting which took place on 20 May 2020 the conclusion was reached that the insertion of a PEG was in GTI's best interests. The decision was then taken to issue proceedings in the Court of Protection in order to seek the court's authorisation for that operation on the basis that GTI lacked capacity to take the decision himself and that the consensus of all present was that it was in GTI's best interests to urgently undergo the insertion of a PEG. The clinical team hoped to carry out the procedure on the afternoon of 22 May.

The Official Solicitor was notified of the application on 21 May, and the application came before Williams J on 22 May, who heard it remotely by Zoom. GTI had told the Official Solicitor that he did not want to participate in the hearing. The same was also true of GTI's mother. It was clear that GTI did not want a PEG, making clear to the solicitor instructed by the Official Solicitor that he viewed it as intrusive and holding "a strong belief that he could if given the

opportunity eat and drink normally. He expressed the view that imposing the procedure on him was reminiscent of the behaviour of dictators and was not the sort of thing that was acceptable" (paragraph 22). GTI's mother did not want to take a position which set her against GTI's wishes. She hoped that ultimately the court would take responsibility.

As to capacity, Williams J declared himself satisfied that:

45 [...] GTI currently lacks capacity to take a decision for himself. The overwhelming weight of the evidence supports the conclusion that GTI is either unable to understand the information about the risks or his inability to take food or drink by mouth or that he is unable to use or weigh that information. These functional deficits are a consequence of his schizoaffective disorder; perhaps in part because the persecutory nature of the disorder leads him to question the reliability of the medical advice or perhaps in part is because of concrete thinking which prevents him considering alternatives to his own formulation of his situation.

Importantly, Williams J did not stop there, but considered (as is not always the case) whether any practicable steps could be taken to support GTI to make his own decision, but concluded that:

45 [...] There is no means by which he could currently be enabled to make a decision save perhaps by authorising the treatment in order to restore proper nutrition and thus enable the resumption of the administration of enteral clozapine. On the evidence currently available it is possible to say that the current lack of

capacity is likely to endure for some months if not years if his previous history of adapting to necessary change is an indicator.

Turning to best interests, Williams J set out in some detail the medical evidence, and also GTI's wishes, before:

Drawing all of the various threads together in relation to whether it is in his best interests I conclude that it is. I say that because

- a. The medical evidence makes it clear that GTI cannot receive adequate nutrition through eating or drinking nor by any alternative means.
- b. If he does not receive adequate nutrition his decline will continue his malnutrition will worsen and he is at risk of dying from starvation.
- c. The evidence demonstrates that GTI does not wish to die but that he derives pleasure from his life; not just eating and drinking but various aspects including socialising and his interests in cars and music.
- d. In order to restore his mental health he needs to be able to resume taking clozapine which he will only be able to do if his physical health recovers such that his body is able to handle its administration without the risk of agranulocytosis.
- e. Although his mother does not wish to oppose GTI's expressed wishes I feel confident that she wishes him to improving his physical and mental health and that the idea of him dying of malnutrition / starvation would be profoundly distressing for her which he would not want her to suffer.

Williams J was clearly troubled by the fact that

he was making a decision that was going against GTI's expressed wishes, noting at paragraph 60 that he was:

particularly conscious of the insult to GTI's personal autonomy of imposing a medical procedure on him against his wishes. Although I am satisfied that he lacks capacity to make the decision it is he who has to live with it not I. I take seriously what he said to Mr Edwards, not only the fact of the PEG being intrusive, but more importantly, that the state overriding his wishes and imposing a medical procedure on him would be experienced by him as a gross insult to his personal autonomy and dictatorial. How would I feel were that to be done to me I ask rhetorically. Of course, it is almost impossible to provide an answer given that the situation GTI finds himself in is beyond my ability to truly understand. If I were to suggest that I might feel angry and violated I doubt that it does justice to GTI's position. However there is another side to this from GTI's perspective I think. I do note though that GTI said his mother means the world to him. I also see that he speaks positively about his life prior to his injury. He enjoyed socialising and would like to expand his circle of friends. He aspired to meeting a partner. He emerges as an intelligent and articulate man who has much to live for. I do not believe that he wishes to continue on a slow decline towards malnutrition, starvation and death. I do not believe he would dream of putting his mother through that appalling process. I believe he would wish to resume as good a life as was possible given the cards life has dealt him. That appears to have been his attitude before and the evidence of those who have been involved with him for some years appears

to support the likelihood of him adapting and making the best of his situation again. Thus, whilst I accept that in approving the carrying out of this procedure I am overriding his wishes, I believe that in the short, medium and long term it is the best course for him and I hope that at some point in the future he might (even if only to himself) see that was so.

Finally, and in a helpful reminder of where the buck stops, Williams J noted that:

61. The Court of Protection exists to take decisions such as this. It not the decision of the hospital or any of the members of staff, nor that of GTI or his family or of the Official Solicitor. Ultimately the state has delegated the making of decisions such as this to the judges of the Court of Protection and it is we who bear responsibility for these decisions.

Comment

Over and above the (enormous) significance to GTI himself, the case provides a useful illustration of how judges are striving in a way frankly inconceivable when the MCA came into force to seek to construct decisions around the starting point of P's wishes and feelings. As Lieven J had done in <u>PW</u>, another case in which the person expressed a clear wish not to die, but was refusing the one treatment that could keep them alive, Williams J did not simply proceed on the basis that the medical evidence gave the answer, but rather sought to recognise (to respect, using the language of the CRPD) both GTI's rights, will and preferences, and that those did not all line up neatly.

The reminder that the buck does stop with the

Court of Protection was crisply and neatly put – and of no little importance. It was not a failure on the part of the medical team that the decision came to be taken by Williams J (although one might ask why it did not come somewhat earlier) but a necessary consequence of the fact that the magnitude of the interference with GTI's Article 8 rights took this out of the scope of those decisions it was appropriate for the clinicians alone to be responsible for.⁴

Advance Decisions to Refuse Treatment – the backstory to a tragic case

We reported in 2018 upon the judgment of Hayden J in <u>NHS CCG v Rushton</u> [2018] EWCOP 41, a deeply sobering case in which Mrs Rushton's attempts to ensure that her decisions regarding future treatment were respected by making an ADRT were stymied until – belatedly – the Court of Protection was able to step into her shoes.

A <u>Safeguarding Adults Review</u> report (and – short – <u>learning brief</u>) has now been published by Cumbria Safeguarding Adults Board into her case. ⁵ The report provides a significant backstory to the circumstances under which Mrs Rushton suffered the traumatic head injury which brought into hospital, as well as rather more detail than is provided in the judgment of Hayden J about the various clinical decisions that were taken resulting in the insertion of a PEG which was (he found) contrary to her ADRT. The story told in the SAR about Mrs Rushton's situation, and, in particular, the role of her

youngest son in her life, is a complex and disturbing one; for present purposes, we limit ourselves to the SAR's conclusions in relation to the ADRT, which were as follows:

7.20 The core purpose of adult care and support is to help people to achieve the outcomes that matter to them in their life (12). The outcome desired by Robyn and articulated in her Advance Decision was not achieved. A number of factors contributed to this. Firstly, there appears to have been only one copy of the Advance Decision and this was placed in Robyn's GP records. There should be a system in place, subject to the consent of the person making the Advance Decision, to ensure that Advance Decisions are shared with other parts of the healthcare system which may have a need to view the Advance Decision at some stage. It would also be helpful for the person making the Advance Decision and her family to retain a copy. In this case Robyn's family were not in possession of a copy of the Advance Decision which could have assisted them in their discussions with hospital staff following their mother's admission in December 2015.

7.21 Professionals may also need guidance on how to advise people who wish to make Advanced Decisions to ensure that they state their wishes as clearly and comprehensively as possible. Professionals may also need guidance on how to interpret and apply what is written in Advance Decisions to the circumstances which subsequently arise

⁴ For ways in which this can be framed in ECHR terms, see this article <u>here</u>.

⁵ Oddly, and probably reflecting the fact that SARs are required to be anonymised, the report refers to her as

[&]quot;Robyn," when it is clear – and in the public domain in the form of the judgment of Hayden J – that her first name was Jillian.

for the maker of the Advance Decision. In this case the GP, to whom Robyn was very well known, interpreted the Advance Decision more narrowly than did the Court of Protection.

7.22 In this case there is disagreement between the family and the hospital over whether the former mentioned Robyn's Advance Decision to the latter. The family are adamant that they notified the hospital of the Advance Decision on three separate occasions. There is no record of these notifications in the hospital records shared with this review. Professionals need to be advised to record any reference to an Advance Decision and then make enquiries to locate the document.

7.23 When the hospital decided to investigate Robyn's Advance Decision, they relied on the GP's interpretation of the contents of the document rather than requesting a copy to consider, although the now retired GP has advised this review that he sent the hospital a copy but this is not confirmed by the GP or hospital records. This is an insufficiently robust approach to considering such an important document. Professionals need to be advised to obtain a copy of any Advance Decision and to seek advice on the interpretation of the content of the document where necessary.

7.24 Cumbria Safeguarding Adults Board may wish to arrange for the learning arising from the handling of Robyn's Advance Decision to inform national guidance, specifically in respect of the need for professionals to advise people who wish to make Advanced Decisions to ensure that they state their wishes as clearly and comprehensively as possible, the need for a system, subject to the

consent of the person making the Advance Decision, to ensure that Advance Decisions are shared with other parts of the healthcare system which may have a need to view the Advance Decision, the need for professionals to record all references to the existence of Advance Decisions and the need to obtain a copy of any Advance Decision and to seek advice on the interpretation of the content of the document where necessary.

The case of *MSP* discussed elsewhere in this Report stands as a further reminder, if reminder is needed, of the importance of the matters set out here in the SAR. Some relate to individual responsibilities, but others relate to how systems do (or do not) respond to the attempts made by individuals to plan for their future.

MCA/DOLS: DHSC additional guidance

On 29 May 2020 DHSC provided some <u>additional</u> <u>guidance</u> to that given in April 2020 on the MCA and the DOLS safeguards during the pandemic, as well as updating the April guidance slightly, and providing a Welsh translation and an Easy Read version.

The additional guidance touches on the following issues.

First it addresses the question of testing someone for Covid-19 where they lack capacity to consent to this themselves. The guidance reminds decision makers to apply the MCA when making best interests decisions on this issue. It also provides that 'For many people, a best interests decision to test for COVID-19 will align with the decision that we could have expected the person to have taken themselves if they had capacity.'. A very strong nudge as to what

decision that may be is given in the following sentence where it states that 'it is reasonable to conclude that most people leaving hospital for a care home, with the relevant mental capacity to take the decision, would have agreed to testing, for the protection of their own health, and others around them." [We cover the question of testing in more detail in our Rapid Response guidance note here].6

Secondly, the guidance addresses again the question of life saving treatment for Covid patients. This is defined in the guidance as treatment to prevent the deterioration of their condition (given the fact there is no cure for Covid). The guidance reminds us that that where life saving treatment is given to a person who lacks capacity to consent to it, that is materially the same as would normally be given to those without a mental disorder, then this will not amount to a deprivation of liberty. This is in line with the Court of Appeal decision in *R (Ferreira)* v HM Senior Coroner for Inner South London and others [2017] EWCA Civ 31. As with the April guidance, the May additional guidance goes further than Ferreira by extending the logic to care homes as well as hospitals, and (potentially) the definition of 'life-saving' treatment from the category of "life-saving emergency medical treatment" that Lady Arden at least had in mind as being encompassed by Ferreira (see paragraph 120 of Re D, when, now as a Supreme Court judge, Lady Arden outlined

what she considered she and other members of the Court of Appeal had decided).

Thirdly it reminds us that life-saving treatment cannot be given if it is contrary to a valid and applicable advance decision to refuse treatment made by the person.

The guidance then goes on in Q&A format to address the question of DOLS and how this is to operate during the pandemic. The guidance provides as follows:

- IMCAs and RPRs need to continue to represent and support those subject to DOLS, keeping in touch with them with remote techniques. Face to face visits should only be made if absolutely essential due to someone's communication needs, if it is urgent, or where there is a concern about their human rights. Presumably this means a concern over and above the fact that they are being deprived of their liberty (which is of course an interference with the person's article 5 rights).
- Where changes to the arrangements to a person's care and support are made during the pandemic, these do not need to be reviewed or notified to the Supervisory Body unless they are 'much more restrictive' than the previous arrangements. The example given is that if a person is not able to have face to face contact with family but is able

capacity to make a decision about their own testing. If the person lacks the relevant mental capacity to consent to the test, and they are aged 16 or over, you should consider if the principles of the Mental Capacity Act 2005 allow you to make a 'best interests decision' to swab and receive results, on their behalf." The same also appears in the quidance in relation to non-Randox test kits.

⁶ Note also in relation to testing the <u>guidance</u> given to care homes when they apply for the relevant Randox test kits (at page 8): "[y]ou should obtain consent to conduct the test from the resident, consulting family members and their GP as appropriate and in line with your usual policies and procedures. Some residents, for example some people with dementia, learning disabilities or mental health conditions, may lack the relevant mental

to have remote contact, then this would not call for a review as this is not a much more restrictive arrangement.

- That in light of what is likely to be a reduced pool of available options on discharge from hospital to a care home, it is likely to be in the person's best interests to be discharged to the 'first appropriate care home'.
- In community settings where a best interest decision is made that a person should socially isolate and this amounts to a DOL, then a Court application should be made.

Lastly the guidance addresses the emergency public health powers. It emphasises the importance of supporting those who lack capacity, and who are exhibiting Covid symptoms, to understand what is being asked of them in terms of following public health guidance. The first step is to assist the person to make the decision to isolate themselves.

Where restrictions are required, whether these can be imposed using the MHA and the MCA must be explored first. Only where these regimes are not available (presumably either because the person does not meet the criteria for detention -MHA – or the restriction in question cannot be said to be in the person's best interests but is required instead to protect public - health -MCA), should the public health powers be considered. In such cases the Local Health Protection Team must be contacted. The guidance sets out the procedure that must be invoked in such cases, to ensure P's participation. The guidance also provides the mechanism for appealing such a decision - to the magistrates court, and makes clear that it is possible for an application to be brought on

behalf of the person where they lack the capacity to do so, and that this may in some cases, be necessary even if the person is not objecting or does not appear to understand that they can make a challenge.

The CQC, MCA and DoLS

The CQC has published <u>guidance</u> on working within the MCA during the pandemic. This makes the very important point that there have been no changes to the MCA and DOLS legislation as a result of the pandemic. It goes on to say as follows:

- Imposing social distancing, restrictions on movement, or isolation in response to coronavirus (for example confining a person to a room) may not in itself amount to a deprivation of liberty.
- Where life-saving treatment is being provided in a care home or hospital, including for the treatment of coronavirus, then the person will not be deprived of liberty as long as the treatment is the same as would normally be given to any person without a mental disorder. (as noted above this is consistent with the Court of Appeal decision in *Ferrerira*, although extending its logic).
- Most changes to a person's care or treatment during the pandemic period will be covered by the existing standard authorisation, however, a review may be necessary in order to decide if a new authorisation is needed to replace the existing one.
- If a person is reasonably suspected as being "potentially infectious" (as defined in the

Coronavirus Act) it is crucial to contact the NHS to ensure the individual receives the right care at the right time.

- When deciding whether to use the MCA or the Public Health Powers to lawfully restrict a person's movements, consideration should be given to the person, family and carers wishes and feelings; whether a best interests decision applies; and whether there is an existing DoLS authorisation in place – these factors point towards using the MCA.
- Providers should continue to notify CQC of the outcome of a standard DoLS application once it is known. There is no need to tell the CQC at the application stage or about urgent self-granted authorisations.

The CQC has also <u>published</u> some information setting out how it is dealing with DoLS during the pandemic.

The CQC have 'paused' their routine inspections of services, instead using the emergency support framework [ESF] which is to apply to all health and social care settings registered with them. This is a flexible approach involving the following elements:

- using and sharing information to target support where it's needed most
- having open and honest conversations
- taking action to keep people safe and to protect people's human rights
- capturing and sharing what the CQC do.

Where however there are serious concerns which cannot be addressed through monitoring

and discussion the CQC will inspect, provided these visits can be undertaken safely. The question of whether there are risks related to deprivation of liberty remains an important one to consider when determining whether to inspect and visit a service.

It remains to be seen whether the CQC will alter the approach set out here in light of the recommendations of the Joint Committee on Human Rights in its report upon the impact of COVID-19 crisis upon young people with learning disability and/or autism detained in psychiatric settings (covered in the Wider Context report).

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Conferences

At present, most externally conferences are being postponed, cancelled, or moved online. Members of the Court of Protection team are regularly presenting at webinars arranged both by Chambers and by others.

Alex is also doing a regular series of 'shedinars,' including capacity fundamentals and 'in conversation with' those who can bring light to bear upon capacity in practice. They can be found on his <u>website</u>.

Advertising conferences and training events

you would like your conference or training event to be included in this section in a subsequent issue. please contact one of the editors. Save for those conferences or training events that are run by non-profit bodies, we would invite a donation of £200 to be made to the dementia charity My Life Films in return for postings for English and Welsh events. For Scottish events, we are inviting donations to Alzheimer Scotland Action on Dementia.

Our next edition will be out in July. Please email us with any judgments or other news items which you think should be included. If you do not wish to receive this Report in the future please contact: marketing@39essex.com.

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