



Welcome to the October 2024 Mental Capacity Report. Highlights this month include:

- (1) In the Health, Welfare and Deprivation of Liberty Report: what to do where there is no reliable evidence of P's wishes and feelings;
- (2) In the Property and Affairs Report: gifts, attorneys and deputies;
- (3) In the Practice and Procedure Report: the perfect as the enemy of the good, and what to do when the situation changes;
- (4) In the Mental Health Matters Report: the human rights consequences of outsourcing in the mental health context;
- (5) In the Wider Context Report: the Law Commission consults on disabled children's social care law and the Grand Chamber of the European Court of Human Rights balances Articles 2 and 8 in the medical treatment context ;
- (6) In the Scotland Report: AWI legislative reform on the cards?

There is one plug this month, for a [free digital trial](#) of the newly relaunched Court of Protection Law Reports (now published by Butterworths. For a walkthrough of one of the reports, see [here](#).

You can find our past issues, our case summaries, and more on our dedicated sub-site [here, where you can also sign up to the Mental Capacity Report](#).

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

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HEALTH, WELFARE AND DEPRIVATION OF LIBERTY

What to do in the absence of wishes and feelings

Northumbria Healthcare NHS Foundation Trust v HX, CX, SX [2024] EWCOP 52 (T3) (Cusworth J)

Best interests – medical treatment

Summary¹

HX was in her late 40s and suffered a cardiac arrest resulting in severe and irreversible brain injury with no prospect of recovery. She had been living with her son who opposed the withdrawal of treatment. Although they had not previously discussed end of life care, his view was that she would have wanted treatment “to make her better or at least make her comfortable and give herself time to make a recovery”. Whereas her mother’s view was that HX would want to be alive in these circumstances. The truth, however, was that there was very little evidence available as to what HX would want for herself in this situation. The hospital applied for a declaration that it would be lawful and in her best interests to receive palliative care.

Cusworth J reviewed the medical and family member’s evidence. The main issue was whether there should be a delay before the decision was made. The medical evidence was that no treatment was available to improve her condition, and that further time would not be in her best interests. There was concern that she was unlikely to physically survive her illness or her admission to critical care over the coming weeks. If she did survive, she would do so to a catastrophically diminished level of neurological function. It was unlikely that HX would regain use of her higher functions (thoughts, feelings, communication, self-awareness, agency).

His Lordship decided that a delay would give the family more time to come to terms with her condition but would not serve to enable any treatment which could alleviate it. Although it could not yet be determined whether or not HX would eventually come to be diagnosed as being in a vegetative or minimally conscious state, it could be said with a very high degree of probability that her recovery trajectory would not enable her to progress beyond those levels. As Cusworth J noted at paragraph 63:

I must accept that if I had clear evidence that HX would favour a continuation of life-sustaining treatment in her current condition, it would be likely to be in her best interests for such treatment to continue. However, when I come to balance the factors for and against continuing the treatment, I am not able to include HX’s views as a determinative factor.

Instead, continued treatment would cause her great pain and distress if she were able to experience it, and that was all that lay before her with no real hope of recovery. His Lordship could not find that, if she had known of the situation that she would find herself in, she would have chosen to remain in her current condition indefinitely, with no prospect of ever returning to any level of function. Considering all the evidence, it was decided to be in her best interests to begin to implement for her a palliative care regime, the consequence of which (but not the aim) would be the end of her life.

Comment

This decision illustrates both the importance of knowing what P would want given their current predicament and the approach to be taken where P’s view is not ascertainable. Following the line of case law since *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, it reflects the importance of considering best interests from P’s vantage point. This CRPD-inspired move away from objective balance sheets towards P’s perspective challenges the autonomous and non-

¹ Note, Nicola having been involved in the case, she has not contributed to this note.

autonomous decision-making binary in seeking to empower those who cannot decide themselves. However, as Lady Hale observed in *Aintree*, it is “*still a “best interests” rather than a ‘substituted judgment’ test, but one which accepts that the preferences of the person concerned are an important component in deciding where his best interests lie.*”

Short note – when to rely on clinical willingness

Re CD (Treatment: Haemodialysis) [2024] EWCOP 55 T3 concerned a 66 year old man with end stage renal disease and dementia. He had been receiving haemodialysis since 2022, but following a third stroke in the summer of 2024, he had repeatedly pulled out the long-term catheter required for haemodialysis to be provided to him twice weekly. A short-term catheter had been inserted but could not remain in situ much longer, and the applicant Trust considered that the point had been reached where continued dialysis and insertion of catheters was not in his best interests. The court refused their application for declarations in support of that position. The Trust’s evidence was that some doctors considered it unethical to insert a further catheter, but that there was one doctor who was willing to carry out the procedure if the court determined it was in CD’s best interests. The evidence was that with a catheter and continued haemodialysis CD might live for 3-6 months and without it for only 1-2 weeks. There was a 10% chance the operation to insert the catheter would result in CD’s death, and a further 10% chance that he would suffer another complication such as a further stroke. He would likely require monitoring and the use of mittens to prevent him pulling out the catheter again. Despite being seriously ill and approaching the end of his life, CD was able to demonstrate joy in the company of his family and was able to sing – there was ‘*a mix of burdens and benefits*’ of continued life for CD. The court was told that some patients with capacity in CD’s position would choose to continue with haemodialysis and others would not. CD’s family were adamant that he would choose to continue – although as a Muslim he would not have wanted to suffer an intolerable burden from medical treatment, that stage had not been reached and he continued to enjoy aspects of life notwithstanding his illness. Weighing up all these factors, the court concluded that continued treatment was in CD’s best interests and made a declaration that it was “*in CD’s best interests and lawful for him to have a new tunnelled haemodialysis catheter inserted under sedation or general anaesthetic and to receive haemodialysis thereafter subject to any significant change in his clinical presentation and provided that the treating clinicians are willing to offer this treatment.*”

It is rightly unsurprising in a case where the medical evidence is that some patients with capacity would choose treatment and others would not, that the best interests decision is strongly influenced by the evidence of what the particular patient would have wanted and to reach a decision that gives effect to the patient’s likely wishes or values. The declaration made hints at the difficulty that the parties in this case might find in the near future – whether doctors would continue to be willing to offer to re-insert a catheter under sedation or general anaesthetic to CD given the predictable deterioration in his condition, and whether agreement might be reached about when the burdens of treatment outweighed the benefits. To an observer, the case appears ideally suited to mediation given the apparently common ground that at some point it would be appropriate to move CD to palliative care to maximise his quality of life as he approaches his death.

Best interests on appeal

MA v A Local Authority & Ors [2024] EWCOP 48 (T2) (HHJ Smith)

Best interests – contact

Summary

This judgment (from February 2024 but only recently made available on Bailii) considered an application to appeal the decision we covered in the [July 2024](#) report of District Judge Simpson to bar two spouses (MA and AA, both of whom lacked the material decision-making capacity) who had been married for more than 60 years, to be separated and have no contact with each other.

HHJ Smith, hearing the appeal, noted that there was no dispute that MA and AA lacked capacity to make decisions about their residence, care and contact with others. They were each deprived of their liberty in separate care placements; MA was considered to have challenging behaviours, and AA had significant health issues. They were initially placed in a care setting together, and it was reported that MA had resisted care being administered to AA, resulting in a deterioration of his condition. AA was hospitalised after a fall, and placed on a different floor of the care home when he was discharged; MA was not informed of this, and they were effectively separated from January 2023. In March 2023, the Court of Protection authorised a move for MA to a placement that was considered better suited to meeting her needs, with a plan to reintroduce contact between MA and AA. At an MDT meeting in May 2023, professionals considered that contact was detrimental to both MA and AA and should end. MA had not wished to engage in video contact.

The appeal was brought by the Official Solicitor on behalf of the wife, MA, and was opposed by the Official Solicitor acting on behalf of the husband, AA, as well as by an ICB and local authority which were responsible for providing their care.

HHJ Smith refused preliminary applications by MA that the appeal should be heard by a Tier 3 judge, and further evidence should be submitted. A rolled-up hearing on permission and the substantive appeal was listed on the eight grounds of appeal, set out at paragraph 20:

- Ground 1: 'When determining MA's best interests under s.4 MCA 2005, insufficient weight was placed on MA's past and present wishes and feelings';
- Ground 2: 'Insufficient weight was placed on AA's past and present wishes and feelings';
- Ground 3: 'Insufficient weight was placed on the mutual beliefs and values of both MA and AA that would be likely to influence their decision if they had capacity. The length of their marriage was compelling evidence of beliefs and values that would likely influence their decisions if capacitous and should have formed an integral part of the court's analysis.'
- Ground 4: 'the judge's analysis on the benefits/burdens of a move for AA to a separate placement was wrong in law,' as the judge saw 'no tangible benefit' to AA of such a move. This was resisted on behalf of AA as there was a complete lack of evidence that AA wished to live closer to MA.

- Ground 5: 'The judge's best interests' analysis on the benefits/burdens of contact between MA and AA was wrong in law as key factors are omitted.' A primary criticism under this ground was 'that the judge was wrong to produce only one table which dealt with both protected parties together. There should have been two separate and person-specific tables within the judgment, before a holistic decision was taken in respect of each protected party....Furthermore, there was a lack of evidence upon which to conclude that the option of exchange of letters and photographs was not available given there had been no proper trial of this means of contact.'
- Grounds 6 and 7: 'set out criticisms which go to overall approach adopted by the judge and raise no separate grounds but go to the balancing exercise. The appellant contends that the approach taken by the judge was overly risk-averse and, in respect of telephone contact, that the judge erred in his application of *Aintree University Hospitals NHS Foundation Trust v James* 2013 UKSC 67, formulating the wrong question.'
- Ground 8: 'The judge erred in his analysis under Article 8 ECHR and failed to provide adequate reasons for this decision.'

HHJ Smith granted permission to appeal on the first seven grounds, on the basis that the appellant had demonstrated an arguable case in respect of the overall balancing exercise undertaken by the judge. However, the appeal did not succeed on any ground.

After considering the "proper approach of an appellate court to a decision of fact by a court of first instance," HHJ Smith found that:

25. An error in findings as to wishes and feelings - past, present or both, has potential to undermine the validity of the overall best interest's analysis given the importance they are afforded in the statute and authorities. However, the finding complained of cannot be said to be wrong rather, it somewhat diminishes the strength of MA's present wishes. I do not accept that the judge mischaracterised MA's wishes nor that he reduced them to such extent that, if more firmly found in terms of strength and consistency and applied in the balance, it would have made any difference to his overall best interest's assessment.

[...]

28. The failure to include the wishes and feelings in the balance sheet against the backdrop of lengthy written analysis within the body of the judgment is of little or no consequence and, in terms of any diminution by the judge's finding in terms of the strength of MA's wishes. Even if the judge made the strongest possible finding as to MA's wishes and feelings and consistency of expression, (which would not have been sufficiently nuanced or appropriate in any event) and found them to be the same as her past wishes, I am not persuaded that such a finding would or should have tipped the balance in terms of the balancing exercise under s4 Mental Capacity Act 2005.

29. In assessing and thus ascertaining MA's wishes and feelings the judge was entitled to draw not only upon her expressed words but also her behaviours and conduct which, as he notes, seemed to contradict her express wishes, and do not include any recognition or understanding of AA's failure to recognise her or the consequent distress this causes her. The District Judge was certainly entitled to conclude on the evidence that MA's requests to see AA were diminishing somewhat. Even if a more nuanced finding that MA's wishes to have contact continue to be daily and sometimes even vehemently and indignantly expressed, "people have pinched my husband", they

would have to be placed in proper context. The judge expressly acknowledges the evidence that MA would be devastated if told she could no longer have contact with AA and weighed it in the balance.

[...]

32. The judge rightly, as in the case of MA, considered words and actions. He was entitled to examine AA's better presentation, the fact he is settled and presenting more happily and does not ask to see MA. His findings as to AA's wishes and feelings were consistent with the evidence before him, and I am not persuaded that any criticism can properly be advanced in terms of the weight the judge afforded AA's wishes and feelings - past or present in the circumstances of this case. It is clear that the judge fully engaged with the competing arguments advanced before him and undertook the necessary evaluative process, in accordance with the evidence.

HHJ Smith also noted that at the hearing, all "parties accepted that face to face contact was not an available option given the difficulties and distress it caused MA and the consequential refusal on safeguarding grounds of both placements to facilitate it. Video contact also made MA distressed because AA would wander off. Continuing attempts at video contact at the time the judge heard the case had not got off the ground because MA was refusing it (and getting irritated by the requests which the court found could impact the good relationship between MA and the witness)" (paragraph 38).

In respect of the other grounds, HHJ Smith consistently found that DJ Simpson had considered wishes, feelings, values and beliefs, and these had 'weighed heavily' on him, as had the value they had placed on the marriage. "It is plain from the entire tenor of the judgement that the court grappled with the issues on the basis that contact was the starting point rather than discounting it lightly as contended by the appellant" (paragraph 45). HHJ Smith considered that the first-instance judge "was in the best position to determine the facts and to identify what was of most relevance to the decisions he had to make" (paragraph 47). She accepted "the proposition that such moments are intrinsically precious having value in themselves in that very moment, even if memories are not expressed, retained, or formed. I also note the point that MA was distressed when she saw J which gives context to her refusals to engage in video contact. However, the judge was faced with continuing refusals and concern that repeated requests would make MA resentful of those asking. He could not ignore that evidence, nor could he look at the earlier evidence of positives from the Spring without considering the later and more recent evidence given the degenerative and progressive nature of dementia as opined by Professor Burns. The judge rightly had to consider frustration, distress or anger occasioned by AA's inability to engage and would have been wrong to ignore it" (paragraphs 48-9).

HHJ Smith dismissed some of the latter grounds as follows:

57. Bluntly, the appellant's approach of minute scrutiny takes no account of the realities which faced the court. All evidence militated against AA being able to appreciate any such proximity or being able to manage MA's unfortunate behaviours in contact (even if a taxi ride were the key impediment to face to face contact) and thirdly, the application of judicial common sense that a move would be disruptive. I guard against any temptation to substitute my own view, but it is also clear that there was no evidence to support the contention that MA would benefit either from AA being geographically closer or that it may or may not increase her distress knowing he is so close but not responding. The overwhelming evidence was that AA is content, has made friends,

including J, is relaxed and positive about his placement. I agree with the submission of Mr Garlick that not one piece of the evidential jigsaw supports such a move other than an assumption as to current wishes and feelings which ignore the realities. Even if it would better reflect long engrained values and beliefs, there was no evidence that AA wished to move in order to live closer to his wife. The District Judge was entitled to find that it was "clear and obvious".

In relation to Article 8, HHJ Smith found that

62. The declaration sought in respect of breach of MA's article 8 rights after AA's fall in January when there was no capacity or best interests' assessment in respect of contact was not raised properly before the District Judge and thus cannot give rise to a ground of appeal, notwithstanding the judicial remarks recorded in the order of Judge Temple. My reading is that District Judge Simpson understood that he was being asked to make declaration as to ongoing breach. Defects in pleadings cannot be made good at the stage of appeal.

63. As to breach of MA's article 8 rights, the court sanctioned the separation in March 2023 and approved staged approach to contact about which the judge heard much evidence. At paragraph 31 of the judgment, he addresses article 8 rights which are always accommodated in evaluation of best interests. He expressly sets out that the decision he has made is necessary and proportionate to protect MAs best interests. He need not, in a separate analysis devoted to European Convention rights, repeat all that he has already set out in his lengthy and careful judgment. His reasons had already been clearly stated and were soundly based on the overwhelming evidence.

Comment

Over and above providing a further snapshot into the types of case which occupy the Court of Protection far more routinely than the ones which are heard by Tier 3 judges, the judgment reinforces how difficult it is to appeal a decision about the evaluation of best interests.

The Ombudsman, triaging and legal realities

Old-fashioned novels sometimes have elaborate subtitles. We might slightly impertinently suggest that if such a novel was being written about the decision of the Local Government and Social Care Ombudsman in the complaint against Stockport Metropolitan Borough Council ([23 009 985](#)), it would have the subtitle "in which the Ombudsman recommends that a local authority does something legally impossible." The complaint arose out of significant problems in the DoLS authorisation process for a Mrs Y. The story is summarised elegantly in the [article about the case](#) in the Local Government Lawyer, and we do not repeat it here. For present purposes, what we want to note is that one of the agreed actions was that "within three months, the Council will review its triaging procedures for DOLS requests to ensure they comply with the requirements of Schedule A1 to the Mental Capacity Act 2005."

The small problem with this agreed action is that there is no 'triating' procedure within Schedule A1 to the MCA 2005. Schedule A1 was enacted on the basis that:

- In the event of a planned move into hospital or a care home, the standard authorisation procedure would and could be completed before the move took place (an authorisation being capable of taking effect up to 28 days after it is granted).

- In the event of a situation which could genuinely not be anticipated, and in which an urgent authorisation could therefore be in play, the process of considering whether to grant a standard authorisation would and could be completed before the urgent authorisation expired.

Schedule A1 is self-evidently law that does not match current realities, such that 'triaging' to identify which deprivations of liberty are 'merely' technical, and which are (or may be) causing harm to the person is required. Some might feel that it would be helpful if the Ombudsman (and, for that matter, CQC) explained how to square the law with current realities.

PROPERTY AND AFFAIRS

Gifts and Deputies and Attorneys

The OPG has just published updated guidance to deputies and attorneys on gifts, when they are authorised and when an application to the Court of Protection is needed (or advisable).

The law has changed little recently, as is exemplified by the case references which are all a few years old. That said, this is a useful update, aimed at lay deputies and attorneys but useful also as a first port of call for any professional who has doubts about a possible gift.

The guidance usefully emphasises at the start that consideration must always be given to the question whether P has the capacity to make the decision to make the gift and, in any event, to seek to involve P in the decision making process.

The guidance also usefully draws the distinction between true gifts (the authority to make which is quite limited) and providing for the needs of others where P has an obligation so to do (dependents such as children etc). In the latter case, COP authority is not needed but an application is advised in borderline cases, especially where the dependent is the attorney or deputy.

PRACTICE AND PROCEDURE

The perfect as the enemy of the good

Re PG [2024] EWCOP 49 (T3) (Cobb J)

Best interests – medical treatment

Summary

In this case, Cobb J was asked to determine the capacity and best interests of a woman as regards investigation and treatment of potentially serious conditions including different forms of cancer. The woman had a long-standing mental health condition, which was described as treatment-resistant. She may have been the subject of a serious sexual assault and /or rape, which professionals considered might account in part to her firm resistance to even mildly invasive obstetric and /or gynaecological examination. She was detained under the MHA 1983, but was on s.17 leave to a supported living placement which was described as being successful. Cobb J describes how in the context of unusual bleeding and other gynaecological symptoms:

[t]he clinically instinctive wish to investigate that pathology was met with a strong body of psychiatric opinion by those who know PG well that any investigation into the cause of the presenting symptoms was likely to cause PG significant and enduring distress, and substantially impact on her fragile mental health.

However, and:

54. Regrettably, and for reasons which have not been entirely adequately explained, there was a significant delay in the issuing of these proceedings from the moment when investigations into possible cancer were first flagged in August 2023; this has been, at least potentially, to PG's detriment.

55. It may well be that the delay in the making of the application has arisen from a lack of communication between the two Applicants; this was hinted at by Dr. H. It may be that it flowed from an understandable concern by the Applicants that it would be inappropriate to trouble the court with an inchoate application in the absence of an agreed "fully-worked up" care plan, in respect of the investigations. If so, I would wish to encourage these Applicants and/or any other applicant in such circumstances with such a case, to be less concerned about ensuring that every 'i' is dotted and every 't' crossed before making the application where speed of decision-making may be of the essence: perfect in this instance may well be the enemy of the good. Once it became apparent that NHS Guidance regarding the investigation and/or treatment of PG's condition could not be complied with timeously, and/or where it was clear that PG's treating/receiving clinicians could not agree upon a care plan to facilitate the investigations and/or treatment, the application could or should have been issued. The Court could then have ensured with the assistance of counsel and solicitors that evidence was filed from the necessary factual and expert witnesses to enable the detail of the care plan to be completed, and a decision to be reached promptly in respect of PG's best interests.

When the application was brought, there was ample evidence that PG lacked the capacity either to conduct the litigation or to consent to medical treatment, in particular to the investigation and treatment

of suspected gynaecological malignancy. The more difficult question was as to her best interests. Cobb J reminded himself of Baroness Hale's comments in *Aintree* as to the proper approach to best interests, in particular that:

37. It is a "best interests" rather than a "substituted judgment" test, but one which accepts that the preferences of the person concerned are an important component in deciding where his best interests lie..." (Baroness Hale in Aintree (above) at [24]).

And:

39. In this regard, it is appropriate that I should have regard to the quality of life which this patient (PG) would regard as worthwhile; it is clear from the Aintree case that the purpose of the best interests' test is to consider matters from the patient's point of view. As Baroness Hale went on to say in that case, it is not that the wishes of the patient will prevail (assuming that it is possible to determine what those views were and/or are), but insofar as it is possible to ascertain the patient's wishes, her beliefs and values, they should be taken into account in the best interests evaluation (see Aintree at [45]).

Cobb J then asked himself a series of questions: (1) as to the optimal outcome; (2) what PG would want; (3) could she be assisted to cope with investigations and /or treatment; (4) is it in her best interests to be subject to investigation if she never be compliant with treatment; (5) to what extent, if at all, would the force, or restraint, or the administration of sedation, be in her best interests if this were to achieve investigation and /or treatment; (6) is it in her best interests to do nothing; and (7) what as to the wider picture? On the facts of the case before him, he concluded (and – by the end of the hearing – reflecting the agreed position of the parties) that:

59 [...]

iii) It is not in PG's best interests to undergo any of the following investigations of her gynaecological symptoms, examination under general anaesthetic and biopsy, local MRI, CT scan of her whole body;

iv) It is not in PG's best interests to undergo the following treatment of her gynaecological symptoms, either by way of surgery, radiotherapy, or chemotherapy;

v) It is in PG's best interests to receive such palliative care as her clinicians considered to be in her best interests at the time.

60. Based on Mr N's evidence, it appears that PG's demise could be imminent, that is to say, within weeks rather than months. The health and social care professionals looking after her, need to know how to manage all aspects of her demise, both physical and psychological. I shall therefore list this application for further hearing in a few weeks' time to consider the revised care plan which will have as its focus the palliative care arrangements for PG.

Separately, Cobb J also made a community deprivation of liberty order "so that PG's section 3 MHA 1983 order can be discharged, so that her bed in hospital can be released, and her placement can be maintained at York House" (paragraph 61). In light of the delay noted above, Cobb J concluded his judgment by emphasising that:

57. The case nonetheless causes me to emphasise for future reference that where cancer is a suspected pathology in respect of a person who lacks or may lack capacity to make treatment decisions, the Hospital Trusts should not hesitate one moment before bringing the matter before the court. I hardly need to underline here that cancer which is diagnosed at an early stage, when it is not too large and has not spread, is more likely to be treated successfully; where investigation and/or treatment is in respect of someone who lacks capacity like PG, court approval should be urgently sought.

In the instant case, however, Cobb J acknowledged that:

even if the case had been heard last year, PG's resistance to investigation and/or treatment, and the long-term outcome for her, would not have been different, or materially so.

Comment

Procedurally, Cobb J was at pains to emphasise that the perfect can be the enemy of the good when it comes to making applications to court; that, equally, applies to clinicians asking for help from legal. There is nothing wrong, and indeed often much which is very right, with clinicians getting in touch with Trust legal as soon as it appears that there may be an issue which might require resolution. Of course, however, that depends on (1) recognition that there may be an issue; and (2) Trust legal (or external legal advisers) being available and resourced to be able to assist at speed.

Substantively, it is striking, that Cobb J was at pains to point out that the case, in fact, was much more clear-cut than it might have appeared at first blush. It therefore shows how often clarity in the process of decision-making can help strip away unnecessary complexity. Indeed, the careful set of questions Cobb J that set himself which would be equally relevant for any decision-making taking place outside court within the s.5 (and 6) MCA framework. Asking and answering those questions in a suitably rigorous fashion will, in many cases mean that, in fact, judicial endorsement of either treatment or non-treatment is required, given Lady Black's clear statement that "if the provisions of the MCA 2005 are followed and the relevant guidance² observed, and if there is agreement upon what is in the best interests of the patient, the patient may be treated in accordance with that agreement without application to the court" (*NHS Trust v Y* at paragraph 126).

Medicine is a Science of Uncertainty and an Art of Probability

Re NR (A Child: Ceilings of Treatment after Survival of Withdrawal of Life Sustaining Treatment) [2024] EWHC 2400 (Fam) (Family Division (Poole J))

Other proceedings – family (public law)

Summary³

In this case, Poole J dealt with a quite extraordinary set of facts: an order authorising the withdrawal of life-sustaining ventilation which culminated, via circuitous routes and serendipity, to a child,

² Which would include, in a case such as PG's, the relevant NHS guidance for treatment of the (suspected) gynaecological conditions in question.

³ Note: Tor having been involved in the case, she has not contributed to this note.

previously confined to a critical care unit, living at home with his parents.

This case was the third in a series of cases concerning NR, a now four year-old boy, born with a severe brain malformation. In previous hearings in January and April 2024 – *Re NR (A child: Withholding CPR) [2024] EWHC 61 (Fam)*; *NR (A child: Withdrawal of Life Sustaining Treatment) [2024] EWHC 910 (Fam)* – Poole J had made orders, first authorising ceilings of care including CPR and escalation of ventilatory support, neither of which were to be carried out in the event of a deterioration in NR’s health; and subsequently, an order authorising withdrawal of life-sustaining treatment on the understanding that NR would die shortly thereafter.

Poole J had heard evidence at the April withdrawal of treatment hearing that there was “no realistic prospect of NR being able to return home for care” (paragraph 19); that extubation would be “one-way” (paragraph 39); and that there was no prospect of NR moving to fully enteral feeding. In light of this evidence, Poole J had concluded that the burdens of treatment far outweighed the benefits of keeping him alive and granted the Trust’s application for invasive ventilation and life-sustaining treatment to be discontinued.

In the event, as Poole J explained in the September 2024 judgment:

2. Over four months after extubation, not only is NR still alive but he is now living at home. He is breathing for himself. He is fully enterally fed. He is urinating normally having previously had an indwelling urinary catheter. He has confounded all medical expectations and his case underlines the maxim that “medicine is a science of uncertainty and an art of probability.” (Sir William Osler, 1849-1919).

It was in this context that NR’s parents, observant Christians who had never accepted the Trust’s evidence as to their son’s prospects of long-term survival, brought an application for the previous orders establishing ceilings of care and a withdrawal of life-sustaining treatment to be set aside. As Poole J records, in light of their son’s unanticipated survival, NR’s parents considered that their views about NR had been vindicated; they believed that the Trust “[did] not truly value NR’s life” (paragraph 3).

Casting a more positive light on the wholly unexpected outcome, Poole J observed:

16. A decision to withdraw life sustaining treatment is not a decision to bring about the death of a patient, but a decision that the continuation of the treatment is not in their best interests. NR’s survival and progress have shown that the withdrawal of invasive ventilation was indeed in his best interests. At the time, based on the prognoses provided to the Court, I decided that ventilation should cease despite, not because of, the strong expectation that NR would die soon afterwards. I do not wish to minimise the emotional turmoil suffered by Mr and Mrs R and the continuing burdens that NR suffers because of his conditions, but it seems to me to be a wonderful surprise that NR has confounded expectations, that he no longer requires continuing invasive interventions and, in particular, that he has been able to return home to the loving care of his devoted parents.

Poole J noted with approval Tor Butler-Cole KC’s submission on behalf of the Guardian at paragraph 25 that:

in a case such as this where NR’s circumstances are not fully predictable and where the Trust

accepts that new medical evidence at the relevant time may mean that any declaration granted is not in fact followed, the Court should exercise caution before making or continuing any declarations. Baroness Hale endorsed such caution in Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67. In Portsmouth Hospitals NHS Trust v Wyatt [2005] 1 WLR 3995, the Court of Appeal said:

"117. We would, however, as a matter of practice counsel caution in making declarations involving seriously damaged or gravely ill children which are open-ended. In the same way that this court said in R (Burke) v General Medical Council (Official Solicitor intervening) [2005] 3 WLR 1132 that it is not the function of the court to be used as a general advice centre (see para 21 of this court's judgment), it is, in our view, not the function of the court to oversee the treatment plan for a gravely ill child. That function is for the doctors in consultation with the child's parents. Judges take decisions on the basis of particular factual substrata. The court's function is to make a particular decision on a particular issue.

118. As a general proposition, therefore, we have reservations about judges making open-ended declarations which they may have to revisit if circumstances change."

Having reviewed the evidence of NR's remarkable survival and heard of the significant change in his circumstances – which included both a family life at home and visits to the park – both the declaration permitting the withholding of CPR and the declarations regarding ceilings of treatment were discharged.

Poole J's conclusion at paragraph 35 is likely to be cited with great frequency by family members opposing withdrawal of treatment going forward:

This case does not establish that the Court cannot rely on medical evidence as to the prognosis for a critically ill patient. It does show that medicine is a science of uncertainty. The Court has to deal with medical predictions and probabilities and such evidence is very valuable. A prediction should not be disregarded simply because it may prove to be wrong. However, confident predictions are sometimes confounded and the Court must be vigilant and humble in the face of apparent certainty.

Comment

We would expect – indeed, hope, given the profound distress experienced by NR's family – that the facts of this case would remain rather extraordinary.⁴ It remains, however, a useful reminder of the importance for decision-makers in re-examining and revisiting decisions in the context of a changing evidential background. The old adage, "when the facts change, I change my mind" applies: decisions made in the best interests of a child – or P – are not necessarily set in stone. This case reiterates the importance for decision-makers of keeping an open mind in an area of medicine and law which is always evolving.

Short note: excluding observers

In *Stockport MBC v NN & Anor* [2024] EWCOP 51 (T1), District Judge Matharu served a useful reminder

⁴ Some might also think that they serve as a useful reminder of the limits of prognostication relevant to debates about assisted dying.

that, whilst open justice is enormously important, it must take account of P's wishes. As she identified when responding to a request for an observer to attend a remote hearing:

10. These decisions require a balance between the need for open justice and the interests of the protected party not being adversely impacted in any way. I am told that merely knowing that the observer had asked for permission to join the hearing caused her to be very anxious and it was submitted that involvement in the hearing was likely to cause her distress. I am told that her behaviours became "heightened".

Hearing this, "the public observer, having heard all of this, graciously said that she was willing to leave the hearing as she did not want to cause NN distress." As District Judge Matharu noted:

14. The mere fact of being a protected party does not automatically mean that the hearing is to be private; however, this protected party is at risk of not being able to participate fully in a "private" environment where she has fully participated in earlier remote hearings where there was no observer. Her voice should be heard when she has made it clear she does not want an observer to be involved in her hearing.

This also provides us with an opportunity to highlight (in advance of a fuller review on Alex's website), the recent publication of [A Practical Guide to Privacy, Transparency, Reporting Restrictions and Closed Hearings in the Court of Protection](#) (Law Brief Publishing, 2024). This short book by Laura Mannering does precisely what it says on the tin, and will be very useful for those having to navigate these provisions.

Short note: contempt before the court

KL v Manchester City Council & Anor [2024] EWCOP 54 (T1) provides a useful worked example of sentencing for contempt (in the absence of the defendant), following the refusal by the defendant to comply with a Court of Protection order requiring him to vacate a property belonging to P and not come within 200 metres of it.

MENTAL HEALTH MATTERS

Mental Health Act Statistics, Annual Figures

NHS Digital has published the [2023-2024 Annual Mental Health Act Statistics](#). The report notes issues with the data provided, including that not all providers submitted information, and there were issues in data quality with some of the providers which did submit information. The report summarises the following 'key facts':

52,458 new detentions under the Mental Health Act were recorded, but the overall national totals will be higher. Not all providers submitted data, and some submitted incomplete data [...] we estimate there was an increase in detentions of 2.5 per cent from last year. [...] Known detention rates were higher for males (91.4 per 100,000 population) than females (83 per 100,000 population). [...] Amongst adults, detention rates tend to decline with age. Known detention rates for the 18 to 34 age group (135.9 detentions per 100,000 population) were around 62% higher than for those aged 65+ (83.8 per 100,000 population).

Detentions were slightly higher for men than women (91.4 vs 83 detentions per 100,000 population), but there are significant racial disparities in rates of detention per 100,000 population:

White	68.4
Asian or Asian British	82.5
Gypsy or Irish Traveller	93.5
Mixed race	177.1
Black or Black British	242.3

There were also significant disparities in rates of detention for ICB regions, with the NHS Somerset ICB region having rates of detention at 31.2 per 100,000 population, and NHS North Central London ICB having rates of 158.5 per 100,000; this is perhaps unsurprising given the data on rates of detention steadily rising with levels of deprivation in an area:

01 Least deprived	43.4
02 Less deprived	49.9
03 Less deprived	54.9
04 Less deprived	60.0
05 Less deprived	74.4

06 More deprived	84.0
07 More deprived	100.1
08 More deprived	124.2
09 More deprived	137.2
10 Most deprived	151.3

Whilst we wait for further news as to whether and how Mental Health Act reform is to be progressed, some might find of interest this [discussion](#) Alex had with Colleen Simon and John Mitchell about a recently published [discussion paper](#) about the ways in which Approved Mental Health Professionals ('AMHPs') undertake their statutory role of 'considering' patient's cases under s.13 MHA 1983, and why it is dangerous to think of an 'MHA assessment' as a single event.

Separately, the Home Office has [published data](#) from 43 of the 44 police forces in England and Wales, showing that there were 31,213 instances in the year to 31 March 2024 when the police used their powers under s.136 MHA 1983 to remove someone from a public place to a place of safety. This was a 10% drop from the 34,685 in the year to 31 March 2024. Community Care [reports](#) that the National Police Chiefs' Council suggests that the drop in the use of s.136 was partially attributable to the introduction of the Right Care, Right Person policy by forces across England and Wales. However, Community Care also reports that the chairs of the Approved Mental Health Professional Leads Network as saying that "though the decrease in s136 usage may be related to the RCRP, drawing definitive conclusions—beyond anecdotal evidence—is challenging". Michael Brown's post on the [topic](#) on the Mental Health Cop website also poses some interesting and challenging questions about the data.

Outsourcing and the Human Rights Act 1998 – the consequences

Sammut v Next Steps Mental Healthcare Ltd [2024] EWHC 2265 (KB) (High Court (KBD) (HHJ Bird sitting as a High Court Judge))

Other proceedings – civil

Summary

Without straying into politics, is a case which demonstrates the consequences of the fact that much state-funded care – including coercive mental health care – is now delivered privately. It concerns a man, Paul Sammut, who had what was described as a chronic, enduring and treatment resistant schizophrenia. For large parts of his adult life, he was detained under s.3 Mental Health Act 1983. As HHJ Bird (sitting as a High Court judge) identified at paragraph 2 of his judgment:

[...] On 26th February 2018, following a best interests review, he moved from a secure hospital to facility operated by the first Defendant [a private healthcare company, the care being funded jointly

by health bodies and a local authority under s.117 MHA 1983.⁵

2. Whilst resident at the facility, Paul was treated as a person subject to deprivation of liberty safeguards. In fact, although he was deprived of his liberty, save for a very short period when he first moved in, the deprivation was at no time authorised. [it appears, although the judgment is less than clear on this point, that the provider sought an authorisation but it was not considered in a timely fashion by the relevant local authority].

3. Paul died on 20th April 2019. The medical cause of death was found, following an inquest, to be broncopneumonia, large intestinal obstruction and faecal impaction related to the side effects of Clozapine (an atypical anti-psychotic used to deal with the effects of schizophrenia).

Mr Sammut's estate brought a claim against the private healthcare company and the NHS Trust responsible for his care for damages for clinical negligence and for false imprisonment. Each of the claimants brings a claim pursuant to sections 6 and 7 of the Human Rights Act 1998 in respect of each defendant relying on breaches of Article 2, Article 3, Article 5, and Article 8.

The care provider sought to strike out the claim and /or to have summary judgment granted in its favour on the basis that it was not a public authority and so no remedy could be granted under the HRA 1998. Alternatively, it submitted, Article 2 ECHR was not engaged on the facts of Mr Sammut's case.

It was common ground that the private healthcare company was not a core public authority for purposes of the HRA 1998. It was also common ground that he could not benefit from the provisions of s.73 Care Act 2014, as he was not being provided with the care under the 'right' funding arrangements so as to deem the activities of the care provider to be a public function. The key question, therefore, was whether the functions being carried out by it were of a public nature.

In answering this question, HHJ Bird had little truck with the Form 3 completed as part of the DoLS assessment process which had identified that placement was imputable to the State, on the basis (1) that the care was funded under s.117 MHA1983; and (2) that the provider was regulated by the CQC, a state authority. HHJ Bird identified that the question of imputation arose when considering deprivation of liberty, but that this was a different issue to whether the provider's functions were of a public nature.

HHJ Bird therefore directed himself by reference to the decision of the House of Lords in *YL v Birmingham City Council and others* [2007] UKHL 27 and had little hesitation in finding that, applying YL:

50. In my judgment it is clear that the first Defendant's functions were entirely private and (as in YL) it was simply carrying business (which happened to have – at least in the abstract – some social utility) for a profit.

In reaching this conclusion, HHJ Bird found that:

51. The absence of any special statutory power is an important factor. In order to deal with that

⁵ The reference in the judgment to care being funded under s.75 Care Act 2014 is confusing, because s.75 does not relate to funding, but rather to the amendments to s.117 MHA 1983 introduced by the Care Act. It must have been the case that Mr Sammut was only being provided with care funded under s.117 MHA 1983 because, had his case been funded by the local authority under the Care Act 2014, s.73 Care Act 2014 would have been engaged.

absence, the Claimants submitted, in effect, that the court should treat the first Defendant as a body with special statutory powers, in particular powers to deprive Paul of his liberty. The submission was based on the fact that the first Defendant appeared to believe that it had those powers and perhaps on the basis that a knowledgeable observer would know that the only lawful way to do what was being done was through the exercise of such a power.

52. I am unable to accept that submission for the following reasons:

a. As a matter of fact, the first Defendant did not have any relevant statutory power. The outcome of the inquiry is binary: there is either a power or there is not.

b. The estate's claim for false imprisonment relies on the absence of a statutory right to detain (summarised at paragraph 7 of the PAPoC). The assertion that I should treat the first as acting under a statutory authority contradicts that position and would create an inappropriate internal tension in the PAPoC.

c. The argument that the first Defendant (in effect) should not be heard to deny that it was acting under a statutory authority was not directly advanced but is the natural conclusion of the Claimants' position. In my view the argument is untenable for the reasons set out above.

HHJ Bird therefore struck the claim out, but identified that he would in any event grant the care provider summary judgment. He then went, on in the alternative, to conclude that Article 2 was not engaged on the facts of the present case, basing himself on the decision of the Supreme Court in *R (Maguire) v HM Senior Coroner for Blackpool and Fylde* [2023] UKSC 20. He noted that:

66. It is in my judgement clear that the claimants pleaded case in respect of Article 2 is not sufficient to engage Article 2. First, there is no assertion that Paul's life was "knowingly put in danger by denial of access to treatment". There is no sense that the medical practitioners were fully aware that his life was at risk if treatment was not given and, even in the face of such knowledge, denied him that treatment. The "denial" referred to in argument is on its own insufficient to engage Art.2. It is no more than an allegation of (very serious) clinical negligence. It follows that the first type of exceptional circumstance that would justify engagement of Art.2, is absent. Secondly, there is no plea of dysfunction which is "genuinely identifiable as systemic". The pleaded failure to "establish, maintain and apply procedures" is a plain reference to something going wrong or functioning badly not as a result of systemic failures, but as a result of clinical negligence. The remaining particulars simply go to emphasise the seriousness of the clinical negligence claim.

67. I am therefore satisfied that, had I not decided the first Defendant was not a public authority, it would have been right to strike out the Article 2 claim pleaded against the first defendant.

68. I am satisfied, on the proper application of *McGuire*, that it would be inappropriate (and wrong in law) to allow the matter to proceed on the basis, as suggested in the skeleton argument, that "recklessness" as to the risk to life as a result of denial of treatment would be sufficient to engage Art.2. It is the need for "full awareness" that elevates the matter above the realm of clinical negligence. It is therefore plainly, a necessary element if the first exceptional circumstance is to be made out.

Comment

It is important to note that the decision of HHJ Bird did not mean that the estate has no claim against the care provider – the strike out / summary judgment application related solely to the HRA claim against the care provider, not the clinical negligence claim advanced. The decision also did not address the HRA claims against the NHS Trust, pleaded on the basis of breaches of Articles 2, 3, 5 and 8 ECHR.

The judgment does, however, reinforce how limited the HRA is as a tool in respect of ‘outsourced’ care. Mr Sammut’s case was arranged and paid for by the state, and, for purposes of Article 5 ECHR, his confinement was unquestionably attributable to the State.⁶ Staying with deprivation of liberty for a moment, Mr Sammut was, on the face of the judgment, confined in a locked door environment with a secure perimeter fence. Logically, this must have meant that the care provider could not provide him with the care and treatment he required without confining him. To comply with its obligations under Regulation 13 of the Regulated Activities 2008, the care provider could not deprive him of his liberty at the unit “without lawful authority.” Some might feel that the difference between a situation where a person has a statutory power to detain and a position where a person cannot carry out a task that they are being commissioned to do without lawful authority is a distinction without an immediately obvious material difference when deciding if they fall within the scope of the HRA.⁷

Had Mr Sammut’s care been funded under the Care Act 2014, s.73 of the Care Act 2014 would have applied to deem the care provider a public authority. But the local authority’s funding obligation arose under s.117 MHA 1983, so s.73 was not engaged (nor, we note, would it have been engaged had his care been commissioned entirely by the NHS). On the face of the judgment, there is nothing to suggest that the nature of the (coercive) care that he received was any different to that which would have provided had the care been funded under the Care Act. In consequence of that might be thought, by some, to be a funding fluke, Mr Sammut’s estate (and, were he still to be alive, Mr Sammut himself) had no direct recourse against the care provider under the HRA. The Law Commission pointed out the anomalous position as regards rights protection to which this gave rise in the context of deprivation of liberty.⁸ The Joint Committee on Human Rights has done the same in relation to the ECHR more widely,⁹ but to date there has been no appetite to remedy this. In the meantime, the HRA provides a direct remedy in relation to private care providers in respect of far fewer situations than many might anticipate.

⁶ HHJ Bird’s observations about this were perhaps expressed in rather too tentative terms, given the clear Supreme Court authority in *Re D* (see paragraph 43) as well as *Cheshire West* about the operation of state imputability for confinements being carried out by private persons. For what it is worth, Mr Sammut would also undoubtedly be considered to have been deprived of his liberty for purposes of the Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment: see the July 2024 General Comment of the OPCAT Committee on Article 4 of OPCAT.

⁷ It so happens that, in this case, the care provider did take steps to seek such authority, albeit that, pending the completion of the DoLS authorisation process, was both breaching its regulatory obligations under the Regulated Activities Regulations and unlawfully depriving him of his liberty.

⁸ See paragraphs 15.41 to 15.50 of its report on Mental Capacity and Deprivation of Liberty. Full disclosure, Alex was a consultant to the project.

⁹ See paragraphs 85 to 93 of its report on human rights in care settings. Full disclosure, Alex was the specialist adviser to the Committee

THE WIDER CONTEXT

Disabled Children's Social Care

On 8 October, the Law Commission published a consultation paper on disabled children's social care law and whether it meets the needs of disabled children and their families.¹⁰ The Law Commission's provisional view is that:

***The law is out of date.** Under section 17 of the Children Act 1989 a disabled child is a child who is "blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity". This definition is from the 1940s. It came from legislation that was intended to help injured soldiers find jobs after the war. The language used to describe disability at that time is offensive now and doesn't capture the nuances of neurodiversity.*

***The law is inaccessible.** In fact, it is not one law at all. It is a complicated set of rules, instructions and advice contained in numerous Acts of Parliament, regulations, court decisions, Government guidance and local authority policies. The authors of the leading legal textbook on disabled children describe it as "a system of baffling complexity" the navigation of which amounts to "additional tiring and frustrating work". We think that's a fair description.*

***The law is also – potentially – unfair.** It says that local authorities should provide the services that are necessary to meet the needs of disabled children. But whether that happens depends on where in the country the child lives. That wasn't the intention of the legislation.*

The consultation asks a number of questions including:

- Whether there should be a new legal framework for disabled children's social care, taking disabled children out of s.17 Children Act 1989.
- Whether there should be national eligibility criteria for disabled children's social care.
- How we should define disability.
- Whether (and what) statutory principles should apply to decision-making in this area.
- What remedies should be available for children and families when things go wrong?

There are also specific chapters and provisional proposals relating to:

- Participation, including discussion of whether there should be a statutory test to determine whether children under 16 have the ability to make relevant decisions about assessment and care-planning.
- The transition to adult social care, including discussion of the problems that take place where inadequate steps are taken to prepare disabled children for adulthood.
- The intersection with healthcare, including discussion of whether the dividing line between health

¹⁰ Alex is a consultant to the project.

and social care for children should be put on a statutory footing.

The terms of reference for the project do not extend to deprivation of liberty, but a separate research paper has been published on deprivation of liberty in the context of disabled children. It is available on the Law Commission's [website](#), together with a summary of the report, and version in Easy Read.

The consultation is open until 20 January 2025.

The ECtHR and the balance between the right to life and the right to autonomy

Pindo Mulla v Spain [2024] ECHR 753 European Court of Human Rights (Grand Chamber)

Article 8 ECHR – medical treatment

Summary

The decision of the European Court of Human Rights in *Pindo Mulla v Spain* [2024] ECHR 753 is a very significant case about the interplay between Articles 2 and 8 ECHR in the context of the refusal of medical treatment.

Ms Pindo was a Jehovah's Witness, living in Spain.¹¹ Following medical tests carried out between May to July 2017, Ms Pindo Mulla was advised to have surgery. She subsequently issued two documents – an advance directive, and a lasting power of attorney – each recording her refusal to undergo a blood transfusion of any kind in any healthcare situation, even if her life was in danger, but that she would accept any medical treatment that did not involve the use of blood. The applicant indicated that she carried the lasting power of attorney document on her person. The advance medical directive was deposited in the official Register of Advance Directives of Castile and Leon and was accessible to Soria hospital via the electronic system used by health professionals in the region. Under the legal framework in Spain, advance directives deposited in the regional registers are to be copied within 7 days to the National Register of Advance Directives, so as to be accessible to health care providers throughout the country.

On 6 June 2018, Ms Pindo Mulla was admitted to Soria Hospital with serious internal bleeding, causing severe anaemia. That evening, a doctor spoke to her about receiving a blood transfusion, which she refused. She expressed her refusal in an informed consent document, which she and the doctor both signed. The document became part of the applicant's medical file at Soria hospital.

The following day, due to haemorrhaging, she was transferred by ambulance to a hospital in Madrid known for its capacity to provide alternative forms of treatment to blood transfusions. She agreed to the transfer, her understanding being that she could be treated there without resort to blood transfusion. She was accompanied by a doctor with her medical records.

During the journey, the doctor warned the doctors at the hospital in Madrid that her condition was very serious. In light of this warning, anaesthesiologists at that hospital contacted the duty judge for instructions on what to do when she arrived. They indicated that she was a Jehovah's Witness, that she

¹¹ The facts here are largely taken from the press release of the court.

had verbally expressed her refusal of all types of treatment and that her condition would be very unstable upon arrival. The duty judge, who did not know the identity of the patient, nor her precise wishes, transmitted the doctors' request to a forensic doctor and to the local prosecutor and requested their opinion. Within approximately an hour, based on the information received and those opinions, the duty judge authorised all medical or surgical procedures that were needed to save her life.

Treating the situation as an emergency, the usual consent protocol was not followed at the hospital. Surgery was performed that day and three transfusions of red blood cells were administered to Ms Pindo Mulla, who had not been informed of the duty judge's order, despite it having been arranged during her journey to the hospital when it was recorded that "she was conscious, orientated and cooperative", and despite still being fully conscious, as noted in her records, when she was taken to the operating theatre. The applicant, who believed that she was to undergo treatment without blood transfusions, did not reiterate her refusal or refer to any written document stating that refusal. She learned of the precise surgery carried out and of the transfusions the day after the operation.

Ms Pindo Mulla brought proceedings in the national courts, out of principle, to overturn the decision. The decision was upheld on appeal, and her subsequent appeal was declared inadmissible by the Constitutional Court.

Somewhat unusually, her application to the European Court of Human Rights was heard by the Grand Chamber in the first instance (a step which normally takes place in relation to an issue identified by the court as being of particular, wider, significance). Whilst Ms Pindo Mulla relied upon both Article 8 (right to respect for private and family life) and Article (right to freedom of conscience and religion), both she, and her the court, ultimately focused on Article 8.

In the course of a long judgment, the Grand Chamber set out an important series of general propositions, before turning to the application of those propositions to the facts of her case. The Grand Chamber focused, in particular, on the necessity of justification for the interference with her rights under Article 8 ECHR, as follows:

- *On personal autonomy in the sphere of health care*

137. It has long been recognised by the Court that the right to respect for private life encompasses personal autonomy. As stated in the Pretty case, cited above, this is an important principle underlying the interpretation of the guarantees of Article 8 (at § 61; see also Lambert and Others, cited above, § 142). That judgment refers to personal autonomy as the right to make choices about one's body (at § 66; see also Nicolae Virgiliu Tănase v. Romania [GC], no. 41720/13, § 126, 25 June 2019).

138. In the sphere of health care, respect for personal autonomy is a general and fundamental principle. It is safeguarded notably by the universally recognised rule of free and informed consent. The legally competent patient who has been duly informed about his or her health condition and the available treatments, as well as the implications if no treatment is accepted, has the right to freely decide whether to give consent to treatment or to withhold it (see Article 5 of the Oviedo Convention and paragraphs 34-35 of its explanatory report, Article 3 of the Charter of Fundamental Rights of the European Union, and Article 6 of the Universal Declaration on Bioethics and Human rights, all quoted above). The Court has decided a number

of cases involving the issue of consent to medical treatment, which mostly focussed on the need to ensure that the patient is placed in a position to take an informed decision about his or her health care (see as an early authority *Trocellier v. France* (dec.), no. 75725/01, ECHR 2006-XIV, and more recently *Mayboroda*, cited above, § 52, with further references). Another aspect that the Court has examined is whether the consent procedure laid down in the law of the respondent State was correctly followed. In this respect, the Court has stated that even if the Convention does not lay down any particular form of consent, where certain requirements are imposed by domestic law, these must be fulfilled; if they are not, an adequate and effective response to the patient's complaint is required from the domestic system (see *Reyes Jimenez*, cited above, §§ 36-38).

139. As for the refusal of treatment, in *Pretty* the Court stated that while this might lead to a fatal outcome, the imposition of medical treatment without the consent of a mentally competent adult patient would interfere with a person's physical integrity in a manner capable of engaging the rights protected under Article 8 § 1 of the Convention (at § 63; see also *Lambert and Others*, cited above, § 180).

140. The right to refuse medical treatment, specifically the religious objection to blood transfusion, featured in the cases *Jehovah's Witnesses of Moscow and Others v. Russia* (cited above) and *Taganrog LRO and Others v. Russia* (nos. 32401/10 and 19 others, 7 June 2022). As the respondent Government and the intervening Government have pointed out, the context of those cases was very different to that of the present one. They involved the dissolution and banning of Jehovah's Witness organisations in Russia. Consequently, the Convention rights at issue were different, notably those of freedom of association and freedom of religion. The right of the patient to refuse medical treatment was not directly addressed as such. Even so, these judgments may be recalled here inasmuch as they affirm, in relation to Jehovah's Witness beliefs, the principles set out in *Pretty*. In *Jehovah's Witnesses of Moscow and Others*, the Court stated that the freedom to accept or refuse specific medical treatment was vital to self-determination and personal autonomy. A competent adult patient was free to decide on surgery or medical treatment, including blood transfusion. It referred to cases decided in various jurisdictions concerning the refusal of blood by Jehovah's Witnesses in which the position taken was that although the public interest in protecting the life and health of patients was legitimate and very strong, the interest of patient autonomy was stronger still, and that free choice and self-determination were themselves fundamental constituents of life. The Court also observed that in the absence of any need to protect third parties, the State had to abstain from interfering with the individual's freedom of choice regarding health care (see § 136; see also *Taganrog LRO and Others*, cited above, § 162).

- On the duty of the State to protect the life and health of patients

141. As the Court has often affirmed, the Convention must be read as a whole (see, among many authorities, *Haas*, cited above, § 54, and *Lambert and Others*, cited above, § 142). Given that in the present case the applicant was assessed as facing an imminent danger to her life, it is necessary to have regard to the principles that the Court has derived regarding the Contracting Parties' duty to safeguard patients. Thus, in *Lopes de Sousa Fernandes*, cited above, it was stated that the Contracting States' substantive positive obligation under Article 2 requires that they enact regulations compelling public and private hospitals to adopt appropriate measures for the protection of patients' lives (at §§ 166 and 186). A parallel duty

has been derived from Article 8 with respect to patients' physical integrity (see *Mayboroda*, cited above, § 51).

142. In addition, as already noted (see paragraph 125 above), the principles set out in certain cases that concerned end-of-life situations are not, despite the very different subject-matter, devoid of relevance for the present case. The Court emphasised there the necessity of robust legal and institutional safeguards in the relevant decision-making process so as to ensure that a decision of such consequence is explicit, unambiguous, free and informed. The person has to be truly conscious of the implications of what they are asking for and must be protected against pressure and abuse (see in particular *Mortier*, cited above, at §§ 139 and 146).

143. The Court has also adverted to the importance of establishing that the patient still has the capacity to take such a decision, if there are circumstances that may give rise to doubt in this regard. The case of *Arskaya v. Ukraine* (no. [45076/05](#), 5 December 2013) involved a complaint under Article 2 about the failure to protect the life of the applicant's adult son, who died following his persistent refusal of the necessary treatment for a serious respiratory illness. At the time, the deceased had shown signs of mental disorder, but his refusals had nevertheless been taken at face value by the doctors treating him. The Court considered that, from the standpoint of Article 2, a clear stance should have been taken by the medical staff regarding the validity of the deceased's refusal of life-saving treatment so as to remove the risk that that decision was made without a full understanding of its implications. It pointed to the need for sufficient guarantees in this respect, and for a regulatory framework which adequately ensures that, where necessary, a patient's decision-making capacity can be promptly and objectively established via a fair and proper procedure (see *Arskaya*, cited above, § 88).

- On procedural safeguards

144. Finally, while Article 8 does not contain any explicit procedural requirements, it is important for the effective enjoyment of the rights guaranteed by this provision that, where decisions are taken that impinge upon a person's private life, the decision-making process is fair and such as to afford due respect for the interests safeguarded by it. In this regard the Court examines whether, in light of the particular circumstances of the case and notably the nature of the decision to be taken, the person affected has been sufficiently involved in the decision-making process, seen as a whole, to afford them the requisite protection of their interests (see *R.R. v. Poland*, no. [27617/04](#), § 191, ECHR 2011 (extracts)). Such an examination allows the Court to satisfactorily assess whether the reasons adduced by national authorities to justify their decisions were "sufficient" for the purposes of Article 8 § 2 (see *Fernández Martínez v. Spain [GC]*, no. [56030/07](#), § 147, ECHR 2014 (extracts)).

145. Furthermore, in the authorities referred to above, *Lopes de Sousa Fernandes* and *Mayboroda*, the Court stated that the obligation to put in place a regulatory framework protecting patients must be understood in a broader sense which includes the duty to ensure the effective functioning of that framework. The regulatory duties thus encompass necessary measures to ensure implementation, including supervision and enforcement (*Lopes de Sousa Fernandes*, cited above, § 189, *Mayboroda*, cited above, § 53).

The court then set out how to reconcile the different rights and duties at stake, noting that it had not yet had the opportunity in its practice how this was to be done in an emergency situation.

146. [...] It would commence by affirming the position that comes through clearly in its existing case-law in relation to patient autonomy, namely that in the ordinary health care context it follows from Article 8 of the Convention that the competent, adult patient has the right to refuse, freely and consciously, medical treatment notwithstanding the very serious, even fatal, consequences that such a decision might have. It is a cardinal principle in the sphere of health care that the right of the patient to give or withhold consent to treatment has to be respected. As important as that right is, however, its location within the scope of Article 8 means that it is not to be construed in absolute terms. The right to respect for private life, being the broader right that encompasses patient autonomy, is a qualified right. The exercise of any facet of that right may therefore be limited in accordance with the second paragraph of Article 8 (see for example *Pretty*, cited above, § 70).

147. In a situation involving real and imminent danger for an individual's existence, the right to life will also be in play, in tandem with the individual's right to decide autonomously on medical treatment. From the perspective of the State, its duties to ensure respect for both of these rights will likewise be engaged, that is to say its duties deriving from Article 8 and Article 2 of the Convention. Concerning the latter provision, the Court reiterates that the right to life ranks as one of the most fundamental provisions in the Convention and also enshrines one of the basic values of the democratic societies making up the Council of Europe. It requires the State not only to refrain from the "intentional" taking of life, but also take appropriate steps to safeguard the lives of those within its jurisdiction (see *Lopes de Sousa Fernandes*, cited above, § 164, and also *Lambert and Others*, cited above, § 117).

148. While it was stated in *Jehovah's Witness of Moscow and Others* that the public interest in preserving the life or health of a patient must yield to the patient's interest in directing the course of his or her own life, the Court also acknowledged that the authenticity of refusal of medical treatment is a legitimate concern, given that the patient's health and possibly life itself are at stake (see § 138 of that judgment). This is consistent with the requirement that the Court has derived from Article 2 for robust legal safeguards and sufficient guarantees where the patient's very life is at stake, referred to at paragraphs 142-143 above. What must be ensured is that, in an emergency situation, a decision to refuse life-saving treatment has been made freely and autonomously by a person with the requisite legal capacity who is conscious of the implications of their decision (see Article 5 of the Oviedo Convention and paragraph 34 of the explanatory report in relation to this provision, set out at paragraph 72 above). It must also be ensured that the decision - the existence of which must be known to the medical personnel - is applicable in the circumstances, in the sense that it is clear, specific and unambiguous in refusing treatment, and represents the current position of the patient on the matter (see Article 9 of the Oviedo Convention and paragraph 62 of the explanatory report in relation to this provision, set out at paragraph 72 above; see also the *Arskaya* case, cited above, at § 88).

Drawing the threads together, this meant that:

149. It follows that where in an emergency there are reasonable grounds to doubt the individual's decision in any of these essential respects, it cannot be considered a failure to respect his or her personal autonomy to proceed with urgent, life-saving treatment. The Court

observes that this position is fully in harmony with Article 8 of the Oviedo Convention, which permits in an emergency situation an exception, that must be narrowly construed, to the general rule of consent. It also follows from the weight to be accorded to respecting the patient's autonomy that reasonable efforts should be made to dispel the doubt or uncertainty surrounding the refusal of treatment. As the Court has previously observed, albeit not in the same context, the wishes of the patient must be treated as being of paramount importance (see *Lambert and Others*, cited above, § 147). The text of Article 8 of the Oviedo Convention does not further elaborate on what is required in such circumstances. In relation to this provision the explanatory report underlines the need for health care professionals "to make every reasonable effort to determine what the patient would want". What constitutes a "reasonable effort" will necessarily depend on the circumstances of the case and may also be influenced by the content of the domestic legal framework.

150. Where, despite reasonable efforts, the physician - or the court, as the case may be - is unable to establish to the extent necessary that the patient's will is indeed to refuse life-saving medical treatment, it is the duty to protect the patient's life by providing essential care that should then prevail.

The court also addressed the weight to be placed upon the previously addressed wishes of the patient:

151. The Court refers to Article 9 of the Oviedo Convention, according to which the previously expressed wishes of a patient who is not, at the time of the intervention, in a position to express his or her wishes "shall be taken into account". As stated in the corresponding passage of the explanatory report to this treaty, it was not intended that such wishes must be automatically followed in all circumstances. It is acknowledged that there may be a need to verify that wishes previously expressed remain applicable and valid in a given situation (see paragraph 62 of the explanatory report, set out above; see also the World Medical Association's Statement on Advance Directives, quoted at paragraph 80 above).

152. The Oviedo Convention does not enter any further into the arrangements that States must or may make with respect to previously expressed wishes. Nor does Article 8 of the Convention. While the principal institutions of the Council of Europe have taken positions in favour of advance directives and continuing powers of attorney in the medical sphere, the Court notes that, in keeping with their non-binding nature, these positions contemplate considerable discretion for States regarding the status of and the modalities in relation to such instruments.

153. In the Court's view, the aforementioned texts reflect both the complexity and the sensitivity that attach to the introduction and operation of a system of advance medical directives (and similar instruments). As found by the comparative survey that was completed for the purposes of the present case, while a considerable number of Council of Europe member States have specific provisions and arrangements in place for advance medical directives, or for taking into account previously expressed wishes, they have not done so in a uniform manner. In the other States surveyed, domestic law does not include provisions dealing specifically with the previously expressed wishes of patients regarding medical treatment. Therefore, it appears that there is a diversity of practice in Europe when it comes to the modalities for reconciling as far as possible the right to life and the right to respect for the autonomy of the patient by taking account of previously expressed wishes. In light of the above

considerations, the Court takes the view that both the principle of giving binding legal effect to advance directives, as well as the related formal and practical modalities, come within the margin of appreciation of the Contracting States.

On the facts of Ms Pindo Mulla's case, the Grand Chamber noted that the "domestic framework for ensuring that patient autonomy is respected within the Spanish health system appears to be a well-developed one, and its features as such have not been criticised by the applicant. Indeed, it can be said to represent a judicious balancing by the legislature between the fundamental rights of patients, the corresponding duties of the State and weighty public interests" (paragraph 172). However, the framework went wrong in her case:

181. The Court fully appreciates that the actions taken in relation to the applicant on the day in question by the staff of both hospitals were motivated by the overriding concern to ensure the effective treatment of a patient who was under their care, in keeping with the most fundamental norm of the medical profession. It does not question their assessments regarding the severity of the applicant's condition at the time, the urgency of the need to treat her, the medical options available in the circumstances, or that the applicant's life was saved that day.

182. However, the authorisation by the duty judge to proceed with whatever treatment was considered necessary resulted from a decision-making process that was affected by the omission of essential information about the documenting of the applicant's wishes, which had been recorded in various forms and at various times in writing. Since neither the applicant nor anyone connected with her was aware of the decision taken by the duty judge, it was not possible, even in theory, to make good that omission. Neither this issue, nor the issue of her capacity to take a decision,¹² were addressed in an adequate manner in the subsequent proceedings. In light of this, it cannot be said that the domestic system adequately responded to the applicant's complaint that her wishes had been wrongly overruled.

The Grand Chamber identified that "what occurred in this case has caused the applicant significant distress. The Court therefore considers it appropriate to make an award of compensation for non-pecuniary damage" (paragraph 189), awarding her 12,000 euros.

A concurring judgment from Judge Elósegui sought to identify particular features that were required to avoid such a problem arising again in Spain. A concurring judgment from Judges Ktistakis (joined by Judge Mourou-Vikström) regretted that the Grand Chamber had not taken the opportunity "to affirm with clarity the principles of self-determination and personal autonomy." Judge Ktisakis noted that "a pivotal aspect of the (rather paternalistic) perspective in the present assessment is the "appearance" of Article 2 of the Convention and the positive obligations on States," and regretted the prioritising of the judgment of *Lopes de Sousa Fernandes v. Portugal* over the previous judgments relating to

¹² Earlier, at paragraph 177, the court noted that: "[t]he question whether the applicant had the capacity to do so was a crucial one, given that there was an advance medical directive on record to ensure that her refusal of blood transfusion would remain operative in the event of her being unable to take such a decision at the relevant point in time according to Spanish law. Yet that issue was not put to the judge at the outset. While it was alluded to by the forensic doctor during the consideration of the application, it was not expressly addressed in the decision that was given. Rather, it was implicitly answered in the negative with the authorisation that was given to proceed directly with the necessary treatment without needing to obtain consent."

Jehovah's Witnesses, which placed much more weight on Articles 8 / 9. Several of the judges also joined in partly consenting / partly dissenting judgments as to whether the award of damages should have been made.

Comment

This case makes entirely clear, should there be any doubt, that the European Court of Human Rights considers:

- (1) That mental capacity is a valid concept, contrary to the position adopted by the UN Committee on the Rights of Persons with Disabilities.¹³
- (2) That reliance upon the presumption of capacity is entirely wrong where there are reasons to doubt that the patient has the capacity to make decisions about life-sustaining treatment.
- (3) That Articles 2 and 8 require to be balanced, and that balancing act is particularly difficult in the emergency situation.
- (4) That things start to go wrong very quickly, and very badly, if there are inadequate systems in place to make sure that wishes expressed in advance are recorded and brought to the attention of those who need to know them at the right time.

Assisted dying update

It was announced on 3 October that Kate Leadbetter MP will be putting forward a Private Member's Bill in the House of Commons on 16 October to legalise assisted dying for terminally adults in England & Wales. The precise details of the Bill are not available at the time of writing, but we understand that it is likely to be similar to the Bill put forward by Lord Falconer in the House of Lords. We understand that Lord Falconer's Bill will have its second reading in the House of Lords on 15 November. As the Parliament [website](#) explains, Second Reading "is the first opportunity for members of the Lords to debate the key principles and main purpose of a bill and to flag up any concerns or specific areas where they think amendments (changes) are needed." The progress of Lord Falconer's Bill can be followed [here](#).

Some may also be interested to attend [this event](#) – already planned for 16 October, the date on which Kate Leadbetter's Bill is being introduced – in which Alex is taking part wearing his hat as a member of the Complex Life and Death Decisions Research Group. Organised between the group and the Policy Institute at King's College London, it will look at new polling results and tease apart the principle from practice when it comes to the debate on assisted dying.

Readers may be interested to see the [interim report](#) from the Nuffield Council on Bioethics Citizens' Jury exploring public views on assisted dying in England. The report sets out the votes and the

¹³ Despite the extensive references to conventions / recommendations other than the ECHR, the CRPD did not feature at all in the judgment, which perhaps reflects the fact that Ms Pindo Mulla was not identifying herself as disabled. There is an interesting question as to whether, given the expansive definition of disability for purposes of the CRPD, she should have been identified as been.

recommendations. It provides initial insights into the main votes and the key recommendations in the words of the jury members. It does not analyse these findings. A second, main report will be published in early 2025. This will provide a rigorous qualitative analysis of the full jury findings, delving into the rationale behind the jury members' recommendations. It will also include the results of two nationally representative surveys of public views on assisted dying conducted as part of the project.

Consultation on restraint provisions in Mental Capacity Act (Northern Ireland)

The Department of Health in Northern Ireland is consulting on the commencement of the Mental Capacity Act (Northern Ireland) 2016 ss9(4)(a) and 12 which relate to "acts of restraint", and an accompanying Code of Practice. Phase one (October to December 2019) included the implementation the deprivation of liberty safeguards. However, not implementing the restraint provisions has required hospital trusts to seek a declaratory order from the High Court with significant resource implications.

Section 9 provides a general defence to liability based on P's incapacity and best interests, and s.12 provides additional safeguards for restraint, namely:

... D reasonably believes—

(a) that failure to do the relevant act would create a risk of harm to P; and

(b) that the relevant act is a proportionate response to—

(i) the likelihood of harm to P; and

(ii) the seriousness of the harm concerned.

The provision includes the instructing or authorising of another person to restrain, and an "act restraining P" is one which:

(a) is intended to restrict P's liberty of movement, whether or not P resists; or

(b) is a use of force or a threat to use force and is done with the intention of securing the doing of an act which P resists.

These provisions are similar to ss.5-6 of the MCA 2005 but there is no explicit statutory requirement to reasonably believe that the restraint is necessary; instead a failure to restrain must create "a risk of harm to P" which is arguably a lower threshold. However, this is partially compensated by the draft Code which expects a risk assessment to determine the need and appropriateness of any restraint. Interesting, the Code includes within the definition of restraint not just mechanical, physical or chemical forms but also "restrictive choice, such as not showing a person where the door to leave is; and withholding information, such as not telling a person where he or she is being taken to prevent resistance" (para 2.4). Moreover, and in line with the approach taken in Northern Ireland which seeks to incorporate public protection squarely within the MCA framework, "Harm to P could also include harm to another person where there is resulting harm to P" (para 2.9).

The consultation runs from 9th September 2024 to 1st December 2024 at 17.00.

SCOTLAND

Forthcoming AWI amending legislation

A Bill described as “a first step to update and modernise the Adults with Incapacity (Scotland) Act 2000” will be introduced by Scottish Government into the Scottish Parliament during the current 2024-25 parliamentary session. It will be one of 14 Bills to be introduced by Scottish Government over the course of the session, to be added to the Parliament’s legislative workload in addition to 12 Bills already before the Parliament, according to the Programme for Government 2024-25 announced by First Minister John Swinney on 4th September 2024 (too late to be covered in the September Report).

The announcement describes the proposed Bill as follows:

“The Bill will be a first step to update and modernise the Adults with Incapacity (Scotland) Act 2000 in line with developing thinking and international standards on human rights. It will ensure adults are supported to make and act upon their own decisions for as long as possible. The Bill will also introduce proposals to modernise how adults with incapacity can participate in research in Scotland, whilst continuing to ensure the rights, safety, dignity and wellbeing of these research participants are prioritised throughout the process.”

This follows upon publication on 25th July 2024 of Scottish Government’s “[Adults with Incapacity Amendment Act Consultation](#)”, on which we did report in the [September Report](#). That consultation closes on 17th October 2024. Any readers who have not yet responded accordingly still have time to do so.

The First Minister’s announcement also intimates that Scottish Government will continue to develop other proposals for legislative change for the next parliamentary year and beyond. Intriguingly, the announcement states that these further proposals will include:

“our commitment to ensure that the rights of neurodivergent people and people with learning disabilities are respected, protected and championed, by publishing draft provisions for a Learning Disabilities, Autism and Neurodivergence Bill. Work will also continue to develop proposals for Human Rights and Ending Conversion Practices.”

It will be interesting to see the correlation among the AWI Bill, the envisaged Learning Disabilities, Autism and Neurodivergence Bill, and the proposed human rights legislation. It will also be interesting to see what is included in the AWI Bill, and what is not. The process of updating and modernising, assuming that this will include all necessary reforms which have been “on the table” for some time during which they have become increasingly urgent, will mean that a quite massive Bill is to be expected.

In the meantime, the workload for Scottish Government officials engaged in the topic of AWI reform will increase substantially as work that has been moving slowly or not at all must now proceed in a very short timeframe. Indeed, at a webinar on AWI reform hosted by Edinburgh Napier University’s Centre for Mental Health and Capacity Law on 1st October 2024, it was indicated that we should expect an accelerated process leading up to introduction of the Bill, with less consultation (or at least less time for consultation) on the proposed drafting of the Bill before it is lodged.

We shall continue to report relevant developments as they come to our notice.

Adrian D Ward

Scottish Government's Adults with Incapacity Amendment Act Consultation: some deprivation of liberty observations

Introduction

There are only a few days left before the deadline for responses to the Scottish Government's Adults with Incapacity Amendment Act consultation on 17th October 2024.

Broadly, the consultation paper, mentioning many of the Adults with Incapacity (Scotland) Act 2000 (AWIA) relevant [Scott Review recommendations](#) and those of the Three Jurisdictions project [report](#), states that the Scottish Government is seeking views on suggestions that will improve access to justice for, and shift the focus of attention to, adults with incapacity, as well as enabling easier access to rights and ensuring supported decision-making for adults with incapacity.

This comes after well over a decade of identifying the need for changes prompted by, amongst other things, the 2004 European Court of Human Rights *Bournemouth* ruling, followed by the 2014 UK Supreme Court *Cheshire West* ruling, highlighting AWIA Article 5 ECHR incompatibility issues relating to the deprivation of liberty ('DoL') of adults with incapacity. It has involved a Scottish Law Commission review, Scottish Government activity and related consultations in 2016 and 2018, the Scott Review (Scottish Mental Health Law Review (2019-2022)) all of which have considered ECHR and CRPD compatible approaches to the deprivation of liberty of adults with incapacity.

The proposals concerning deprivation of liberty are set out at various points in the consultation paper and these will not therefore be reiterated here. However, it might be worth considering some of these and the possible human rights questions they raise. More detailed discussion of the human rights framework in Scotland and implications for deprivation of liberty can be found in the [March 2024](#) issue of the Mental Capacity Report.

The AWIA consultation deprivation of liberty (DoL) proposals

The consultation paper proposes that welfare attorneys be empowered by the adult to authorise and consent to a DoL (when the adult has lost capacity).¹⁴ It asks for views on this and also on how (including how often) a placement should be reviewed where the adult has been deprived of their liberty as well as views on any appeal process.

Whilst it seemed to have been accepted by the Scottish Courts that Article 5 ECHR compatibility can be achieved through relevant guardianship powers, the Court of Protection in [Aberdeenshire Council v SE](#) pointed out that the lack of ability to challenge an unlawful DoL authorised by a AWIA guardian was incompatible with Article 5(4) ECHR there being no real review and appeal process. The consultation

¹⁴ Having spent far too long on these issues in England & Wales, Alex, pedantically, would point out that for Article 5 purposes, consenting to a DoL is logically impossible. One either consents to confinement, or (being unable or unwilling to consent to that confinement) is deprived of one's liberty. This confusion in language runs through the consultation, making some of the proposals conceptually headache-inducing.

paper therefore proposes six monthly reviews and that there be an express right of appeal against the lawfulness of the DoL if authorised by either a welfare attorney or guardian. Further, a standalone right of appeal is also proposed, not dissimilar to that already found in the Mental Health (Care and Treatment) (Scotland) Act 2003.

These proposals – particularly when accompanied by the proposals to amend the AWIA principles to give precedence to the adult's will and preferences and the need to demonstrate, before intervening without consent, that all attempts at supporting the person's legal capacity have been exhausted – certainly bring us closer to Articles 5 and 8 ECHR compliance. This is of course, provided that in all cases the reviews are triggered automatically and regular.

There is currently no clear steer from the European Court of Human Rights as to whether advance, or proxy, consent to the authorisation of a DoL is compatible with Article 5 ECHR. However, as the Scott Review final report discussed, whilst this is not perfect, then provided the nature and extent of the DoL is specified and mechanisms are in place to ensure that any subsequent departure from the adult's advance authorisation is heeded such an approach arguably supports the adult's autonomy insofar as is possible. This, of course, does not fully address the Committee on the Rights of Persons with Disabilities General Comment No. 1 direction that guardianship be abolished, although it does suggest a framework for ensuring serious attempts are made to ensure that a DoL is the last resort, after considering how to attempt to meet the adult's needs in other ways (reflecting the adult's will and preferences about the life they wish to lead). It also takes account of ECHR jurisprudence that makes it clear that it must not be assumed that a person who is considered to lack the ability to exercise their legal capacity (which obviously includes to consent to a confinement) are unaware, and have views about, their situation .

That being said, one aspect of the consultation which will require much more consideration going forward is that of instigating challenges, appeals, to the lawfulness of the DoL. The European Court of Human Rights ruling in *MH v UK* is clear about the fact that such processes must be 'practical and effective' for the person concerned. A statutory right of appeal of itself is meaningless if the adult does not know about and understand such a right, and/or where support to instigate such a challenge is not readily available through friends, family or professionals. The consultation paper suggests that the Mental Welfare for Scotland's role be extended to permit it to investigate any AWIA DoL placement where concerns are raised with the Commission by any person having an interest in the adult's welfare, or by the Commission itself in the course of its visiting function for those adults who are not already subject to formal authorisation and review measures. However, this arguably does not go far enough.

A word about delayed discharge

Concerns over 'bed blocking' have been raised for a long time now. Insofar as this concerns adults who may lack capacity for whom there is no immediate process to authorise the move the person from hospital to a community-based care setting, the consultation paper asks for views on using different care settings outside the NHS for persons no longer requiring acute hospital care (but who do not have guardianship in place). It specifically asks what issues should be considered here.

It is important to appreciate that if a person is in any care setting (NHS or otherwise) where there are deprived of their liberty there must be a lawful process to authorise the DoL, regular reviews and a

practical and effective means by which to challenge the lawfulness of the DoL. To seek to circumvent this is likely to have serious ECHR, and CRPD, implications. When the Equality and Human Rights Commission initiated action in 2020 against NHS Greater Glasgow over a similar arrangement it became clear that there were adults who did not wish to be in a care home who were placed there against their will (see the [November 2020](#) issue of Mental Capacity Report for a discussion of these proceedings, which were eventually concluded without a reported judgment). Independent scrutiny is therefore essential here.

Conclusion

We know that there appears to remain to be an appetite within the Scottish Government to reform the AWIA. Its June 2023 response to the Scott Review indicates this, with AWIA reform being amongst the immediate priorities of its programme of mental health and capacity law reform over the next 10 years. Moreover, the introduction of an Adults with Incapacity Amendment Bill into the Scottish Parliament was expressly mentioned when it announced its Programme of Government 2024/25 in September 2024.

Many of the Scott Review recommendations were made in light of the Human Rights Bill promised by the Scottish Government which, it was envisaged, would increase the range of legally enforceable rights, including those identified in the CRPD, particularly economic, social and cultural rights, in Scotland. However, progress on this Bill appears to have stalled.

What the Adults with Incapacity Amendment Bill will look like will only become clearer when it is introduced into the Scottish Parliament. Obviously, amending the AWIA as it stands by giving the adult's will and preferences precedence and introducing greater safeguards against inappropriate and unlawful deprivations of liberty can only secure an adult with incapacity's ability to live as unrestricted and autonomous life as possible to some extent. It is entirely possible to try to seek alternatives to deprivations of liberty and other restrictions on autonomy by identifying alternatives to getting a person's needs met. Leveraging access to the necessary support and services to achieve this is considerably enhanced by the presence of legally enforceable economic, social and cultural right together with adequate resourcing and structural and institutional change. Whilst overly bureaucratic processes can be cumbersome and, in fact, might have the opposite effect to safeguarding rights in that they become mere 'tick box exercises', expediency must not thwart the protection and ensuring of the rights of adults who fall within the AWIA remit.

Jill Stavert

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Conferences

Members of the Court of Protection team regularly present at seminars and 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 [website](#).

Adrian will be speaking at the European Law Institute Annual Conference in Dublin (10 October, details [here](#)).

Peter Edwards Law have announced their autumn online courses, including, Becoming a Mental Health Act Administrator – The Basics; Introduction to the Mental Health Act, Code and Tribunals; Introduction – MCA and Deprivation of Liberty; Introduction to using Court of Protection including s. 21A Appeals; Masterclass for Mental Health Act Administrators; Mental Health Act Masterclass; and Court of Protection / MCA Masterclass. For more details and to book, see [here](#).

Advertising conferences and training events

If 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 November. 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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