



Welcome to the November 2018 Mental Capacity Report, including from the newest recruit to the editorial team, Katherine Barnes. Highlights this month include:

(1) In the Health, Welfare and Deprivation of Liberty Report: an update on the Mental Capacity (Amendment) Bill; sex, risk and public anxiety; and a slew of significant decisions relating to medical treatment;

(2) In the Practice and Procedure Report: Sir James Munby addresses the LAG Community Care Conference and updates from the Court Users Group;

(4) In the Wider Context Report: relevant developments from around the world, including an important decision from Australia reflecting back on practice under the MCA;

(5) In the Scotland Report: a report from the World Guardianship Congress, and the impact in Scotland of an important case concerning disability discrimination and autism.

There is no Property and Affairs Report this month as our editor is having a well-earned break; but he would relay to you if here the frustrating news of the delay to the Law Commission's project on [wills](#).

You can find all our past issues, our case summaries, and more on our dedicated sub-site [here](#).

Editors

Alex Ruck Keene
Victoria Butler-Cole
Neil Allen
Annabel Lee
Nicola Kohn
Katie Scott
Katherine Barnes
Simon Edwards (P&A)

Scottish Contributors

Adrian Ward
Jill Stavert

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

Contents

Mental Capacity (Amendment) Bill Report stage	2
Sex, risk, and public anxiety	3
Novel treatments and best interests.....	4
Will vs preferences in action?	6
Sex, contraception and the courts.....	7
The importance of a natural death.....	9
Dementia, nutrition and equality of arms.....	11
Risk tolerance in practice	15
DoLS statistics.....	16

Mental Capacity (Amendment) Bill Report stage

Ahead of the Report stage of the Bill on 21 November, the Government has proposed a series of amendments. They are available [here](#), although are somewhat impenetrable in their published form. Helpfully, Tim Spencer-Lane has summarised the effect of the key ones as follows:

1. Extending the Liberty Protection Safeguards to 16 and 17 year olds;
2. Replacing the term “unsound mind” with “mental disorder;”
3. Explicitly stating that the cared-for person must be consulted with;
4. Explicitly stating that the cared-for person’s wishes and feelings must be considered as part of the necessary & proportionate assessment;
5. Requiring responsible bodies to decide if care home managers should arrange the assessments and statement or if the responsible body takes on these functions;
6. Requiring that assessments cannot be carried out by someone with a financial conflict of interest;
7. Confirmation that the responsible body arranges the pre-authorisation review;
8. A duty to appoint an IMCA if a person doesn’t have an ‘appropriate person’ representing them, unless it is in the person’s best interests not to have an IMCA;
9. Removing the requirement that a care home manager must notify the responsible body whether or not an IMCA should be appointed;
10. Requiring that medical and capacity assessments must be completed by those with appropriate experience and knowledge.

One obvious omission from the list is the

statutory definition of deprivation of liberty that Lord O'Shaughnessy indicated on the second day of Committee stage the Government would attempt.

Further briefing documents have been published by, amongst others, the Law Society; updates on the Bill's progress can also be found on Alex's website.

Further briefing documents have been published by, amongst others, the Law Society; updates on the Bill's progress can also be found on Alex's website.

Sex, risk, and public anxiety

Manchester City Council v LC [2018] EWCOP 30 (Hayden J)

Best interests – contact – mental capacity – sexual relations

Summary¹

This case, concerning the sexual relationships of LC, a young woman with autism and a learning disability, received considerable public attention shortly before this judgment was handed down, a Times journalist having been given permission to access documents from the proceedings and to write about them (though without any reasoned judgment being available). The short judgment from Hayden J, who was hearing the case for the first time, summarises the proceedings with the aim of putting properly in the public domain "*the issues that this case raises so that there can be, as there ought to be, appropriate and informed public debate.*"

LC had been found by the court in 2016 to have capacity to: engage in sexual relations; marry; make decisions in relation to contraception. But she was found to lack capacity to; conduct the proceedings; make decisions on her contact with men; make decisions about care and residence; make decisions as to whether to enter or terminate a tenancy; decide whether or not she should access mobile phones or social networking sites.

Hayden J referred to the obvious tension to which these differing determinations of capacity gave rise, saying "[t]hus, though it may not be intuitive, it is perfectly logical, looking at capacity in an issue-specific context (as the MCA requires), to possess the decision-making facility to embark on sexual relations whilst, at the same time, not being able to judge with whom it is safe to have those relations."

At the time of the hearing, LC was living in a residential placement with other young women, having visits from her husband five times a week including two overnight visits.

The court referred to discussion that had taken place at the hearing as to whether these limitations on LC's freedom of action in respect of her marriage could be authorised under the MCA:

There has been a legal argument as to whether the MCA, by collateral declarations, is apt to limit the autonomy of individuals in spheres where they are capacitous. In simple terms, whether the measures put in place to protect LC in

¹ Nicola Kohn being involved in this case, she did not contribute to this report.

those areas where she lacks capacity may legitimately impinge on her autonomy in those areas where her capacity is established. It has been canvassed that if the court is to restrict LC either in part or, potentially, fully in such a sphere (i.e. where she has capacity), the court ought only to consider such measures under the parens patriae jurisdiction of the High Court. Happily, it is unnecessary for me to resolve that issue today, indeed, it may not arise. It does require to be said that whenever a court has to curtail the liberty of an individual whether capacitous or not, the burden is acute and the responsibility grave. In future, it seems to me, where issues arise that may necessitate restrictions in areas where adults have capacity, these should be heard by a High Court Judge in the Court of Protection.

Comment

The full details of the decisions made in LC's case may yet be put in the public domain, as the court directed further expert evidence and a further hearing. From the details in this judgment, it is difficult to have an informed view on the press coverage of the proceedings previously and in particular the decision to allow LC to have male visitors to her property, in accordance with her wishes.

The proposal that cases where capacity and incapacity are found in related areas of decision-making should be heard in the High Court is understandable, but may result in a larger number of cases coming before the High Court than Hayden J anticipated. While he was correct

to say that the reported cases in this arena were all heard by High Court judges, that is, in the authors' experience, more a function of the fact that High Court judges are much more likely to give written published judgments than other judges than a reflection of where these issues are decided.

It is to be hoped that the question of capacity might receive some further clarification in a public judgment in this case. Hayden J refers to the woman having significant learning disabilities, yet she is considered to have capacity to consent to marry and to have sexual relations and to make decisions about contraception, and was able to address the judge on a number of issues.

Novel treatments and best interests

UCLH NHS Trust v KG [2018] EWCOP 29 (Cohen J)

Best interests – medical treatment

Summary and comment²

In this case, Cohen J had to decide whether to give authority to administer an entirely novel treatment to a middle-aged man suffering from sporadic CJD. All agreed, including the Official Solicitor's behalf, that the treatment was in his best interests. It was vitally important that treatment begin immediately, as the man's condition was progressing rapidly.

In approving the treatment, Cohen J identified that the best interests test, here, could be broken down into the following factors (at paragraph

² Tor being involved in the case, she has not contributed to this report.

17):

[first] the nature of the treatment that is proposed, what is involved and what its prospects of success are. Secondly, what are the views of the patient, what does he want and what do his nearest and dearest want? Thirdly, how do I feed into the thought process the fact that this is a novel and experimental treatment.

As to nature, the actual treatment was not hugely invasive, it might require direct placement into the brain, together with continual – and potentially uncomfortable – monitoring. Cohen J identified a series of safeguards that were in place regarding the novelty of the treatment, including (at paragraph 22) that:

Next, the Trust in the middle of this year, anticipating that this sort of case would arise within the reasonably foreseeable future, has been in communication with the Official Solicitor and has had at least one meeting with the Official Solicitor involving the appropriate medical staff. That is a step which I applaud. It means the Official Solicitor has had time to consider all the relevant facts and, even though he was doing so in a vacuum without a patient on hand, it permitted the thought processes about the relevant matters to develop without the pressure of a case that was coming imminently before the courts.

When it came to wishes, it was clear that KG himself wanted it. Perhaps slightly more surprisingly, Cohen J also took into account the wishes of and, impact upon, his family, following *Simms v NHS Trust* [2002] EWHC 2734 (Fam), concerning an (unrelated) 16 year and an 18 year old, in which Dame Elizabeth Butler-Sloss had

noted that:

The impact of refusal by this court of granting the declarations on each set of parents and, in one case, 5 siblings, and in the other case, one sibling, would in my view be enormous and palpable. In a finely balanced case I should give the views of the parents and the effect upon them of refusal great weight in the wider considerations of the best interests test which the court has to apply to each patient.

Cohen J had no hesitation in approving the treatment as being in his best interests.

Two further points of importance arose:

1. In making the application, the Trust made clear that, following the judgment in Y it propose to bring further applications before the court in the event that it proposes to treat future patients with PRN100 and the patient and his/her family are in agreement. Cohen J demurred, noting that:

30. Obviously I am not dealing with other cases, but I would respectfully suggest that it might be premature to arrive at such a conclusion until the results of this treatment are known. It may be that the benefit or risk analysis changes.

31. I do, of course, accept that these cases are extremely urgent and they must be brought on to a hearing with great speed. That this can be done is evidenced by this case, an application issued I think on Thursday last week, possibly Wednesday, and is now before me for a final hearing on the Monday of the following week.

2. The Official Solicitor invited the court to persuade the court that the *Bolam* test was one that should be adopted, drawing attention to the passage in *Simms* at paragraph 42, where the President had said:

First [the doctor] must act at all times in accordance with a responsible and competent body of relevant professional opinion, generally described as the 'Bolam test'... [Secondly] ... a duty to act in the best interests of a mentally incapacitated patient.

However, Cohen J declined to do so, noting (at paragraph 33) that

Simms was a case that pre-dated the Mental Capacity Act, and I do not think it is helpful to layer an additional level of test on top of those which are set out in the Mental Capacity Act.

The test is therefore simply that contained in the MCA, although we would suggest that a doctor who was acting entirely outside the scope of a body of relevant professional opinion would in the ordinary run of events have a difficult time explaining how they could be said reasonably to be acting in the best interests of the patient to whom they were administering the treatment.

Will vs preferences in action?

Re SJ [2018] EWCOP 28 (Moor J)

Best interests – medical treatment

Summary

This case concerned SJ, a 43 year old diabetic suffering from chronic, unhealed bed sores in the context of significant obesity and incontinence.

He had previously been detained under the Mental Health Act 1983 during which time he suffered from psychosis and some form of cognitive decline. SJ's treating clinicians were united in the view that SJ lacked capacity to consent to medical treatment and that the insertion of a colostomy was vital to his recovery and survival. His consultant surgeon Mr V gave evidence – via telephone from a taxi, the pavement outside his home, and his home itself – that without colostomy surgery, SJ was likely to die within 6 months.

SJ's sister MJ opposed the use of a colostomy on the basis that SJ had lost substantial amounts of weight and said he did not want the operation. She disputed the capacity evidence and argued the Court should allow SJ's wishes not to have the surgery to be determinative.

Moor J noted SJ's own opposition to the surgery and, at paragraph 35, the conclusions of Munby J in *Re M; ITW v Z* [2009] EWHC 2525 that "... *the weight to be attached to [P's] wishes and feelings must depend upon the particular context...*"; that the nearer to the borderline of capacity P is, the more weight must be attached to his wishes and feelings; the significance of the strength and consistency of the views P expresses; the possible impact upon him of his wishes and feelings not being given effect; the extent to which P's wishes and feelings are or not rational; and the extent to which P's wishes and feelings could be given effect to within the court's assessment of his best interests. Moor J further noted the conclusion of the Supreme Court in *Aintree University Hospitals NHS Foundation Trust v James* [2003] UKSC 67 as to the starting point being, not the reasonable patient, but the person themselves.

He concluded (at paragraph 42):

I am clear that this is an operation that should now take place as being overwhelmingly in SJ's interests. I take the view that, if he had capacity, he would, in fact, see that and would wish to save his life in that way. There is absolutely no indication that he really wants his life to end. I am quite clear that, if he could understand the evidence that I have heard today from the three doctors, he would say "Judge, I do not know why we are in court; of course I must have this operation. Please do it quickly". Because of his incapacity, he is unable to weigh the matters up in this regard. But for that very reason I take the view that I should overrule his wishes, notwithstanding having very carefully considered all the law on this point and the wishes as he has set them out both to the doctors and to the Official Solicitor

Comment

In many cases, including others discussed in this report, sufficient clarity as to the answer as to what the person would have done would give the answer to what lies in their best interests. In other cases, of which this may be an example, what the person really wants and what they say they want (in CRPD language, what their will is and what their preferences appear to be) are in tension: the best interests test in its post-*Aintree* formulation allows this to be accommodated.

As an interesting aside, the case also provides an example of the robust yet flexible case managing powers available to judges which, it could be argued, more judges in the Court of Protection should exercise. Taking the unorthodox step required in light of the urgency of the case, Moor

J heard evidence from one clinician via phone from a taxi. SJ's sister MJ applied to vacate just 2 days before the hearing. Moor J refused to adjourn but made clear to MJ that he would hear any application to adjourn at court. In the event, MJ failed to appear at court without giving any clear reason why. Moor J concluded that it would help neither SJ nor his sister to adjourn matters, furthermore that the case was too urgent to delay. He therefore granted the order sought by the applicant trust in MJ's absence and held that the matter should also be brought finally to an end.

Sex, contraception and the courts

Re P (Sexual Relations and Contraception) [2018] EWCOP 10 (Baker J)

Best interests – contract – contraception – mental capacity – sexual relations

Summary

This case concerned a young woman with learning disabilities, in respect of whom Court of Protection proceedings had been ongoing for a considerable period of time. In 2012, the court determined that P lacked capacity to make decisions about contraception and consented on her behalf to the insertion of an IUD under general anaesthetic. P was never told about the IUD.

In 2016, the local authority applied to restore the proceedings to revisit the question of P's capacity to engage in sexual relations and to make decisions about contraception, and to consider her best interests and to authorise her deprivation of liberty at her supported living placement.

The court was asked to decide (1) does P has capacity to consent to sexual relations? (2) If she does, what steps should be authorised to facilitate the relationship between P and her boyfriend, or between P and any other person with whom she wished to have a sexual relationship? (3) is the proposed relaxation in supervision in her best interests? In addition, the court reviewed wider issues concerning her treatment, including the question whether it should continue to be covert or whether P should be informed about it.

The court accepted psychiatric evidence that P lacked capacity to make decisions about contraception, residence, care and contact. She was vulnerable to harm from others and could not identify how she would judge whether someone she met posed a risk to her, including with regard to a sexual relationship.

On the topic of capacity to consent to sexual relations, Baker J applied the current caselaw and found that P had capacity, but noted that

many people would agree with the strong views expressed by [P's mother] in a statement filed for the hearing before me in which [she] said inter alia:

"if P lacks capacity to make decisions regarding contact (in particular of people who may cause a risk to her) how on earth can she have capacity in respect of sexual relations? A decision just to have sex with a person surely needs to include a decision based on STDs and other risks involved. Such a decision in my view is narrow-minded and does not include any thought of consequences for care,

accommodation, family etc."

Baker J described the situation as a 'paradigm case' in which P's "*relationships need to be supported, managed and, if necessary, controlled by the court*" in view of her lack of capacity to make decisions about contact but her capacity to consent to sexual relations.

Baker J noted that the IUD had been fitted without any opportunity for P to express her views and that P's care manager said that if P was asked now, it was her view that P would say she did not want the IUD. Nevertheless, the court concluded that it was in P's best interests for the IUD to remain in place for the rest of its natural lifespan, relying on matters including the following:

1. P would suffer emotional and psychological harm if she became pregnant again, particularly if her child was (as had happened previously on two occasions) removed from her care at birth;
2. P had said consistently she did not want to have a baby at this stage;
3. P's mother considered the IUD should remain in place, in light of her concerns about P's vulnerability to abuse;
4. Even though P was subject to 24 hour supervision, there was a very small risk that she would put herself at risk of exploitation;
5. An IUD remained the most reliable form of contraception for P and there was no medical reason for it to be removed.

Baker J further held that it was not in P's best interests to tell her of the existence of the IUD, accepting that the impact on P's relationships

with her family and care team would be put at risk if she lost her trust in them. The judge stated however that this position could not remain forever: *"although I approve the plan to retain the IUD, and not to tell P about it at this stage, I regard it as imperative that professionals working with P keep this issue under review at all times and start planning now for ways in which further decisions about contraception can be taken in a way that includes P and respects her personal autonomy and human rights."*

Finally, Baker J authorised a trial period of reduction in the supervision afforded to P, in light of her wish to have more freedom. The judge recognised that further problems were likely to arise, as P's mother did not support the relaxation in supervision and remained concerned about sexual exploitation, whereas the local authority were taking steps to see whether P's relationship with her boyfriend could be supported. Having approved the reduction in supervision, however, Baker J said that *"I do not consider it appropriate to include in the order a provision that it is lawful for the local authority to facilitate a sexual relationship between P and a potential partner in accordance with the draft care plan."* This was not because (for instance) of the possible risk of complicity in offences under the Sexual Offences Act 2003 on the part of the local authority, but simply because he wanted to take a staged approach in light of the history of sexual exploitation.

Comment

This case is, as the judge observed, a paradigm example of the difficulties that arise when a person is judged to have capacity to consent to sexual relations but not to other, closely related, matters, such as contraception and

contact. The net result in this case was that P was permitted to have some time free from 1:1 supervision, but despite her capacity to consent to sexual relations, the local authority could not 'facilitate' a sexual relationship with her partner. The Court of Protection would remain involved, to monitor and make decisions about P's relationship - despite the low threshold test for capacity to consent to sexual relations having been set at that level at least in part to avoid state interference in people's private lives.

Although Baker J did not say so expressly, the judgment suggests that the approval of covert insertion of an IUD might not have been the appropriate way forward back in 2012. Further, and whilst the judgment in the Y case was still anticipated, Baker J noted that, whatever the Supreme Court might say about bringing applications concerning serious medical treatment to court, *"given the serious infringement of rights involved in the covert insertion of a contraceptive device, it is in my judgement highly probable that, in most, if not all, cases, professionals faced with a decision whether to take that step will conclude that it is appropriate to apply to the court to facilitate a comprehensive analysis of best interests, with P having the benefit of legal representation and independent expert advice."*

The importance of a natural death

Leeds Teaching Hospital v JF [2018] EWCOP 32 (Cohen J)

Best interests – medical treatment

Summary

A 46 year old lady, N, had breast cancer, and had only a number of months to live. Whilst in the taxi on the way to the hospital to seek assistance

after complications with oral medication for her cancer, she suffered a cardiac arrest. For 20 minutes or so ceased breathing and suffered a severe hypoxic injury. In consequence she suffered a very significant and severe brain injury. She remained essentially unconscious. There was no anticipation of any significant improvement in her neurological condition, certainly within the life expectancy of her cancer which was some six to eight months.

Three issues were before Cohen J. The first was whether a tracheostomy tube should be removed; it had been inserted (following approval at an earlier interim hearing) to replace an oral tube which had been causing increasing discomfort and was causing irritation. The Trust sought removal of the tube because they considered that nothing more should be done to extend or prolong N's life. Removal of the tube would have the effect (but not the purpose) of hastening her death, either because N would "*die either by infection of the secretions* [that would build up] *or would drown.*" The family, and the Official Solicitor, wanted to keep it in place; the judge accepted their contention that N would want a natural death, such that it "*would need a very good reason to hasten it in this way.*" Cohen J came to the clear view that the tube should remain in place.

The second issue was as to whether or not N should receive an escalation of invasive care or treatment, in particular vasoactive drugs, renal replacement therapy, ventilation treatment that requires central venous access or CPR. There was agreement in relation to all of these in relation to antibiotics, which the family wanted on the basis that this was "*treatment for a*

super-imposed condition which would not cause her natural death if treated." Cohen J held that antibiotics do not need to be provided in the event of there being an infection and that it would not be in N's best interests to provide treatment to seek to avert what would be a natural death.

The last issue was in relation to the administration of morphine. Although N did not discuss her health in a significant way with her family, she and other members of her family did have a fixed objection to morphine. That came from the fact that two members of the family had died at a time that they were taking morphine which had been prescribed for them as a result of very serious health difficulties which they themselves had. The family had formed the view that morphine had played some part in the demise of those two relatives. Although N was not yet far up the analgesic ladder potentially to require morphine, the evidence from her treating team was that there was no better substitute to morphine. However, her treating doctor accepted that "*if a conscious patient had been able to make a balanced decision that he or she did not want morphine he would not seek to impose it upon the patient.*" Cohen J noted that he, "*of course, ha[d] to take the decision for others, but I bear in mind the strong family opposition shared by N to the use of morphine.*" He therefore authorised medications, but not morphine. However, he gave the Trust permission to apply in relation to morphine if in due course it transpired that there is no alternative that might be able to do the job. As he noted:

Whether the court will order it will depend on the circumstances at that time, but if

all other avenues have been exhausted it seems to me that it would be quite wrong for me to bar the treating team from a position of being able to apply for permission to use morphine in circumstances where their conscience makes this, not only highly desirable, but something that should be imminently implemented.

Comment

Although this case was decided shortly before *Y* (but not reported until more recently) this is the quintessential example of a case which would still be required to come to court even following the clarification of the scope of s.5 MCA 2005 in that case. What does not appear from the judgment in this case is whether mediation was attempted, but, again, this is a paradigm case in which such might have bridged the gap between the family and the treating team as to what was in N's best interests.

Dementia, nutrition and equality of arms

RAO v ROO [2018] EWCOP 33 (Williams J)

Best interests – medical treatment

Summary

In this unusual case, a husband sought orders in relation to medical treatment in relation to his wife, ROO, who was on palliative care in hospital. She had suffered a stroke in 2008, which had serious consequences (inter alia) that she required nursing care in a home thereafter. In 2012, her condition deteriorated, in circumstances that the husband believed had never been adequately investigated, but considered might arise from the consequences of a malfunctioning shunt. Following a move to

a new nursing home in early 2018, her health declined, and she became increasingly resistant to care and regularly refused fluids, food and medication. She was admitted to hospital after her weight had fallen significantly, a diagnosis being made of post-stroke admission. After a period in hospital she was discharged back to the nursing home, but was readmitted shortly thereafter with pneumonia. Attempts to insert a nasogastric tube to assist with nutrition were unsuccessful, although she continued to accept food and drink on occasions orally.

Her husband – acting in person – brought an emergency application in the Court of Protection on the basis that artificial nutrition had been withdrawn and his wife put on palliative care without consultation or agreement, a best interests meeting or an application to the Court of Protection. He sought declarations that: (1) that it was not in best interests to be discharged from hospital in her present condition; (2) that it was in her best interests for her to be taken off palliative care until there had been a full investigation and definitive diagnosis of the cause of her deterioration since 2012; and (3) she be given artificial feeding until she could eat enough to keep her alive.

At an expedited hearing, the Trust invited the court to go beyond the scope of the orders sought by the husband and to make declarations as regards future treatment, in identifying a ceiling of treatment or non-escalation and providing only for palliative care. However, Williams J declined to go down that route having regard to the "*seriousness of the issues that were engaged in pursuing such a course and the lack of notice to [the husband] and the limited time available to the court.*"

The Trust's position was that ROO was suffering from irreversible and progressive vascular dementia, and that she was now in the final stages of her illness which could be a matter of weeks or months but more likely weeks. They do not consider that any further investigations are required to understand her current condition from a neurological perspective. The Trust considered the provision of intravenous nutrition will do nothing to address the underlying condition. If it were provided and weight were gained and it were then withdrawn ROO would simply lose weight again, and that (in fact) weight gain could not assist her to regain the muscle mass she needed to regain organ function. The Trust also identified risks to artificial nutrition, not least that it was likely that ROO would object to the treatment and the resultant higher level of medicalisation that would be involved. The Trust also noted that, as ROO was being provided with antibiotics if necessary, the palliative care described should not be equated to end of life care. The Trust resisted her transfer to another hospital, as she did not need to be an acute medical ward, and would be comfortable and more receptive to her family in the environment of a nursing home.

Williams J summarised his conclusion as to the approach dictated by the MCA in the post-Aintree world thus (at paragraph 35, emphasis in original):

*Therefore, a host of matters must all go into the balance when the judge seeks to arrive at his objective assessment of whether **this** treatment is in **this** patient's best interests. In particular I must consider the values and beliefs of ROO as well as any views she expressed when she had capacity that shed light on the*

likely choice she would make if she were able to and what she would have considered relevant or important. Where those views can be ascertained with sufficient certainty they should carry great weight and usually should be followed; as they would be for a person with capacity who did express such views.

Williams J made clear that each of the three questions before the court on the husband's application depended to a significant extent upon whether there was a definitive diagnosis in relation to the cause of ROO's deterioration since 2012. On a detailed analysis, Williams J was clear the medical evidence that her neurological condition was attributable to those causes which took place in 2008/2012 and subsequent further progressive changes compounded by acute events. They did not result from the consequences of a malfunctioning shunt. He was of the clear view that her condition was irreversible and had been in my view fully explored.

In light of this conclusion, the answers to the questions before him became relatively straightforward. Williams J, however, sought to identify ROO's wishes and feelings to assist, although:

70. The evidence in relation to ROO's wishes and feelings in relation to the application is very limited. She of course does not currently have capacity. She has not given any advance directive in relation to her treatment and there is nothing in writing elsewhere from her which would indicate what her views would be in respect of the treatment proposed. In respect of what she said to the hospital staff and the indication she

gave to Dr Brooke [the hospital had recorded two instances when ROO has said the words 'I want to die'. She also nodded her head when Dr Brooke asked her whether it was true that she wanted to die.] I do not think it's safe to place any reliance on that as her real indication of what she wishes to happen to her. The evidence suggests that at times when she is in a better condition she engages with her children and ROA and takes pleasure from that interaction. She may also still gain pleasure from eating or contemplation. At other times she may have an awareness of her condition and may wonder whether it is worth continuing. In particular if she is feeling unwell she might understandably express a wish to die but I do not think that much, if any, weight can be placed on this in the context of what else is known about ROO. She is described as a fighter, independent, a believer in the circle of life. There are also though indications that while she does not have capacity she is unhappy at intrusive medical treatment or other intrusions into her personal space. She removed the nasogastric tube. She declined medication, food, she does not want a nasogastric tube reinserted. That suggests that she does not welcome further medical intervention, and the more intrusive it is the less she would welcome it. I therefore do not think she would want to be subjected to intrusive treatment which would accompany intravenous feeding. It is clear that an intravenous line would have to be inserted and that it would require intensive medical intervention in terms of monitoring thereafter. I do not consider from what I'm able to glean of her wishes and feelings that she would want this to be undertaken particularly if she knew that the medical evidence was that it would not actually bring any

benefit to her. Nor do I consider she would be likely to want to undergo further investigations such as a further lumbar puncture still less an operation when the medical evidence was that it was neither necessary or appropriate. The evidence is that she needed to be sedated for the 2014 lumbar puncture which indicates that she was not comfortable with that.

Williams J concluded (at paragraph 74) that, as when ROO's best interests were viewed on the broadest perspective, that:

a. Due to the nature of her neurological condition ROO will not recover in a way which will lead to her eating enough to keep her alive. The nature of the progressive vascular dementia that she is suffering from is such that she will sustain loss of appetite and will wish to eat less and less as time passes. That is an inevitable consequence of her condition. There is therefore no prospect of her reaching a position where she can eat enough to keep herself alive in the sense that it appears in the application; namely that she will recover to a position where she will want to and will be able to eat anything approaching a normal diet which would be accompanied by exercise in a way which would sustain her life. Thus having regard in particular to the evidence of Dr Johnston and the guidance on artificial nutrition in patients with dementia there is no benefit to ROO of giving artificial nutrition and nor do I believe she would want to be given it having regard to the intrusive nature of it being administered and the risks of complications which accompany it. I therefore do not consider it to be in ROO's best interests in the circumstances she currently is in to be given artificial feeding by way of intravenous nutrition.

b. The medical evidence clearly establishes the nature of ROO's neurological condition. There has been a full investigation and insofar as medical science allows there is a definitive diagnosis. There is no need or purpose in further investigation or attempts to reach an alternative diagnosis. The only alternative identified by ROA namely the malfunctioning shunt has been comprehensively addressed and discounted by a number of doctors including Professor Whitfield. I therefore do not find that it is in ROO's best interests to have further investigations in order to reach an alternative diagnosis. Dr Brooke told me, as I have referred to earlier, that ROO is still being given treatment for her condition. She is not being treated as an end-of-life patient at the current time. She has been given antibiotics and other medication for instance. In that sense she is not on what ROA describes as a palliative care regime. The evidence is that ROO is in a stable condition and fit to be discharged to a nursing home where she would continue to be nursed in a manner appropriate to her deteriorating condition. I therefore conclude that it is not in ROO's best interests for her to be taken off palliative care until there has been a full investigation and definitive diagnosis of the cause of her deterioration since 2012.

c. The premise underlying the first order that ROA seeks is that ROO should remain in hospital so that artificial nutrition can be administered and so that further investigations can be undertaken. ROA says that she should remain in hospital albeit being transferred to the North Devon hospital nearer to ROA and her sons. The NHS Trust and Dr Johnston

have concluded that there is no purpose to be served in her remaining on an acute medical ward and given my conclusions in respect of artificial nutrition and further neurological investigational treatment, I am in agreement with them. Dr Johnston in particular, having regard to the various guidelines, identified that to maximise the quality of life that ROO has and in particular to maximise the environment in which she takes oral nutrition and is able to interact with people a transfer to a nursing home close to her sons and ROA would appear to be in her best interests. The more relaxed and natural environment of a nursing home would be more conducive to her engagement with her family and other aspects of her life including feeding than the environment of an acute medical ward. I do not therefore agree that it is not in her best interests to be discharged from hospital in her present condition. As matters stand it would appear that her best interests would be met by transfer to a local nursing home.

Comment

The outcome of this sad case is perhaps not entirely surprising, although (read also with *RW*) is a useful contribution to the caselaw on best interests in the context of advanced dementia. However, Williams J was clearly, and rightly, troubled about the fact that the husband in this case was acting as a litigant in person. Whilst he was clearly able to advance his case clearly and cogently, the inequality of arms here was striking – and arguably troubling. One could imagine a compelling argument that where a litigant in person in such a case obtain permission from the court to bring an application (hence filtering out entirely hopeless applications), then they should be eligible for assistance in formulating

their case. One can also imagine (sadly) how that argument would fly with the Ministry of Justice...

Risk tolerance in practice

LB Islington v AA [2018] EWCOP 24 (Senior Judge Hilder)

Best interests – P's wishes – residence

Summary

This judgment of Senior Judge Hilder does not lay down any new principles of law but is an interesting example of the decision on the facts balancing toleration of risks against P's wishes and feelings.

P (AA) was 46 years old and came to England from Bangladesh at the age of 8. She was of Muslim faith and her first language was Sylheti. Her brothers were BA, BB and BC. AA was married at the age of 23 and had two children. The marriage came into an end and AA returned to live with her mother and brothers, without her husband and children.

AA was diagnosed as suffering from schizophrenia and was detained under the Mental Health Act. She was later admitted to hospital and discharged to a nursing home with the agreement of her family. She made trips back to the family home for contact and, on one occasion, the family failed to return AA to the nursing home for several days until social services intervened.

AA is then said to have disclosed to a psychiatrist and a social worker that her brothers abused her. Her brothers denied that any abuse occurred. A few days later, BA took AA out of the nursing home for a walk and did not return her.

When the social worker and police visited the family home, AA said that she wanted to remain there and not to return to the nursing home. Proceedings were then issued by the local authority.

The local authority sought a number of findings of fact which were collected under three separate headings – financial, neglect and physical/verbal abuse. The court found some, but not all, of the allegations to be proven. In particular, the court was considered that AA was at times in a state of health crisis and there were some deficiencies in the care of AA but a basically adequate level of care was provided by her family. There was no evidence at all to substantiate the allegation of continuous severe neglect. In relation to the financial allegations, the court was satisfied that there was some degree of AA's benefits being used as reasonable contribution to combined household costs but the court was also satisfied that there had been significant inappropriate use of AA's funds for matters (including mobile phones and online gambling services) which were not for AA's benefit. AA's standard of living could have been improved by more appropriate use of her funds during the time that the family were the care providers.

In light of the court's findings of fact, the court concluded that it was entirely appropriate that responsibility for AA's finances should no longer lie with family members and the local authority now acted as appointee. In relation to her residence and care, the local authority argued that it was in AA's best interests to move back to HV, a rehabilitation unit, a support AA to gain the skills and confidence in activities of daily living that would facilitate her being able to live as

independently as possible in the community. The family's position was that AA should remain living in the family home. BA said that the family could now manage better than they had in the past.

AA's representative considered that AA should remain at home with a further review by the court in 2 months' time. In particular, giving the continuing clarity of AA's wish to live at home, and the level of distress which had recently been manifested when that wish was not given effect, AA's representative contended on the part of AA that "even if it is not perfect, and is not providing all that a rehabilitation placement can" at this point, it was in AA's best interests to remain living at home.

HHJ Hilder reached the conclusion that it was in AA's best interests to remain at home, at least in the short term, and placed significant weight on AA's own wishes and feelings at paragraphs 90 and 92:

I am concerned that the approach of the Local Authority appears to take too little account of AA's wishes and feelings, particularly in the presently uncertain circumstances of her physical health needs. The aim of rehabilitation is laudable but there is insufficient information available to satisfy me that AA's engagement in rehabilitation is realistically achievable at the moment. I can find nothing to suggest that compelling AA's return to HV now, as the LA seeks, would be any less traumatic to her than Dr Hanlon assessed it to be barely a month ago. If she is traumatised in her return to HV, there must be serious doubt that she would be able to benefit from HV's rehabilitative approach in the short term at least...

I am not satisfied that it would be in the best interests of AA to compel her return to HV against her wishes, even for the laudable aims of rehabilitation support, whilst there is the very real prospect that she will imminently be admitted to hospital, for significant treatment. I am satisfied that it is in the best interests of AA to require further information to be provided about her physical healthcare needs before a final decision is made as to where she should live and receive care. Until that further information is available, in my judgment it is in AA's best interests that she remains living at home with the current care package. I consider that a care package of 4 hours a day, 7 days a week, by independent carers, provides sufficient support for the family so as to mitigate the risks suggested by past crises, and sufficient oversight of the situation for the Local Authority to be able to respond very quickly to any deterioration in AA's wellbeing if necessary. I consider that the family ought to be taken at their word, and given the opportunity to show that they can cooperate with the care package and "do better this time".

Comment

This case is another example of the increasing importance and weight being afforded to P's own wishes and feelings even where it leads to an outcome which might be inherently more risky than the alternative.

DoLS statistics

The most recent DoLS statistics for the period 1 April 2017 to 31 March 2018 have now been published.

There were 227,400 applications for DoLS received during 2017-18, with almost three quarters relating to people aged 75 and over. This represents an increase of 4.7% on 2016-17 although the rate of increase is slowing compared to previous years.

	Applications received	Year-on-year change
2013-14	13,715	-
2014-15	137,540	123,825
2015-16	195,840	58,300
2016-17	217,235	21,395
2017-18	227,400	10,165

Source: NHS Digital

There were more DoLS applications received than were completed (181,785) in 2017-18. The number of DoLS applications that were completed increased by 19.6% from 151,970 in 2016-17. The proportion of these that were granted was 61.1% in 2017-18.

The reported number of cases that were not completed as at year end was 125,630. Of these just under 40% (48,555) were received prior to 1 April 2017 – in other words, had still not been completed at least a year after they had been received.

The average length of time to complete a DoLS application increased from 120 days in 2016-17 to 138 days in 2017-18, although in addition the number of applications completed within 90 days increased by a fifth. Nationally the proportion of standard applications that were completed within 21 days (as required in the regulations and the Code of Practice) fell from 23.3% in 2016-17 to 21.7% in 2017-18. The range of months it would take for local authorities to clear their applications not completed as at 31 March 2018 if they did not receive any new applications, based on their

rates of completion during 2017-18 ranges from 0 months to 61.6 months, the average being 7.6 months.

As in previous years, there was a wide range of variation across the country in the volumes of DoLS applications, their outcomes and how they were administered. As in previous years also, however, the bare statistics are difficult to compare because of the very different practices that different local authorities have adopted in order to try and keep abreast.

The statistics can be fleshed out by reference to the picture of DoLS provided in the CQC’s annual State of Care report for 2017/2018. Although good practice was highlighted in a number of places, as in previous years, the CQC:

continued to observe variation in how care home and hospital providers use DoLS and the MCA. This variation can lead to poor practice and have a negative effect on people using services, for example unnecessary restrictive practices that can result in a loss of freedom. In some cases, these practices can breach people’s human rights. Our inspections found that although most care home providers comply with DoLS legislation, there remains variation in the quality of how the safeguards are applied in services.

Depressingly:

Varied practice appears in different ways depending on the sector, but is commonly linked with a basic lack of understanding of DoLS and the wider MCA. This can then be reinforced by limited staffing levels and a lack of time to complete applications, as well as

inadequate staff training. The general complexity of the DoLS legislation and a lack of local authority resources to deal with the number of DoLS applications also influence varied practice.

Editors and Contributors



Alex Ruck Keene: alex.ruckkeene@39essex.com

Alex is recommended as a 'star junior' in Chambers & Partners for his Court of Protection work. He has been in cases involving the MCA 2005 at all levels up to and including the Supreme Court. He also writes extensively, has numerous academic affiliations, including as Wellcome Research Fellow at King's College London, and created the website www.mentalcapacitylawandpolicy.org.uk. To view full CV click [here](#).



Victoria Butler-Cole: vb@39essex.com

Victoria regularly appears in the Court of Protection, instructed by the Official Solicitor, family members, and statutory bodies, in welfare, financial and medical cases. Together with Alex, she co-edits the Court of Protection Law Reports for Jordans. She is a contributing editor to Clayton and Tomlinson 'The Law of Human Rights', a contributor to 'Assessment of Mental Capacity' (Law Society/BMA 2009), and a contributor to Heywood and Massey Court of Protection Practice (Sweet and Maxwell). To view full CV click [here](#).



Neil Allen: neil.allen@39essex.com

Neil has particular interests in human rights, mental health and incapacity law and mainly practises in the Court of Protection. Also a lecturer at Manchester University, he teaches students in these fields, trains health, social care and legal professionals, and regularly publishes in academic books and journals. Neil is the Deputy Director of the University's Legal Advice Centre and a Trustee for a mental health charity. To view full CV click [here](#).



Annabel Lee: annabel.lee@39essex.com

Annabel has experience in a wide range of issues before the Court of Protection, including medical treatment, deprivation of liberty, residence, care contact, welfare, property and financial affairs, and has particular expertise in complex cross-border jurisdiction matters. She is a contributing editor to 'Court of Protection Practice' and an editor of the Court of Protection Law Reports. To view full CV click [here](#).



Nicola Kohn: nicola.kohn@39essex.com

Nicola appears regularly in the Court of Protection in health and welfare matters. She is frequently instructed by the Official Solicitor as well as by local authorities, CCGs and care homes. She is a contributor to the 4th edition of the *Assessment of Mental Capacity: A Practical Guide for Doctors and Lawyers* (BMA/Law Society 2015). To view full CV click [here](#).

Editors and Contributors



Katie Scott: katie.scott@39essex.com

Katie advises and represents clients in all things health related, from personal injury and clinical negligence, to community care, mental health and healthcare regulation. The main focus of her practice however is in the Court of Protection where she has a particular interest in the health and welfare of incapacitated adults. She is also a qualified mediator, mediating legal and community disputes. To view full CV click [here](#).



Katherine Barnes: Katherine.barnes@39essex.com

Katherine has a broad public law and human rights practice, with a particular interest in the fields of community care and health law, including mental capacity law. She appears regularly in the Court of Protection and has acted for the Official Solicitor, individuals, local authorities and NHS bodies. Her CV is available here: To view full CV click [here](#).



Simon Edwards: simon.edwards@39essex.com

Simon has wide experience of private client work raising capacity issues, including *Day v Harris & Ors* [2013] 3 WLR 1560, centred on the question whether Sir Malcolm Arnold had given manuscripts of his compositions to his children when in a desperate state or later when he was a patient of the Court of Protection. He has also acted in many cases where deputies or attorneys have misused P's assets. To view full CV click [here](#).



Adrian Ward: adw@tcyoung.co.uk

Adrian is a recognised national and international expert in adult incapacity law. He has been continuously involved in law reform processes. His books include the current standard Scottish texts on the subject. His awards include an MBE for services to the mentally handicapped in Scotland; national awards for legal journalism, legal charitable work and legal scholarship; and the lifetime achievement award at the 2014 Scottish Legal Awards.



Jill Stavert: j.stavert@napier.ac.uk

Jill Stavert is Professor of Law, Director of the Centre for Mental Health and Capacity Law and Director of Research, The Business School, Edinburgh Napier University. Jill is also a member of the Law Society for Scotland's Mental Health and Disability Sub-Committee. She has undertaken work for the Mental Welfare Commission for Scotland (including its 2015 updated guidance on Deprivation of Liberty). To view full CV click [here](#).

Conferences

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 December. 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.

Michael Kaplan
Senior Clerk
michael.kaplan@39essex.com

Sheraton Doyle
Senior Practice Manager
sheraton.doyle@39essex.com

Peter Campbell
Senior Practice Manager
peter.campbell@39essex.com



International
Arbitration Chambers
of the Year 2014
Legal 500

Environment &
Planning
Chambers
of the Year 2015

clerks@39essex.com • **DX: London/Chancery Lane 298** • 39essex.com

LONDON
81 Chancery Lane,
London WC2A 1DD
Tel: +44 (0)20 7832 1111
Fax: +44 (0)20 7353 3978

MANCHESTER
82 King Street,
Manchester M2 4WQ
Tel: +44 (0)16 1870 0333
Fax: +44 (0)20 7353 3978

SINGAPORE
Maxwell Chambers,
#02-16 32, Maxwell Road
Singapore 069115
Tel: +(65) 6634 1336

KUALA LUMPUR
#02-9, Bangunan Sulaiman,
Jalan Sultan Hishamuddin
50000 Kuala Lumpur,
Malaysia: +(60)32 271 1085

39 Essex Chambers is an equal opportunities employer.

39 Essex Chambers LLP is a governance and holding entity and a limited liability partnership registered in England and Wales (registered number 0C360005) with its registered office at 81 Chancery Lane, London WC2A 1DD.

39 Essex Chambers' members provide legal and advocacy services as independent, self-employed barristers and no entity connected with 39 Essex Chambers provides any legal services.

39 Essex Chambers (Services) Limited manages the administrative, operational and support functions of Chambers and is a company incorporated in England and Wales (company number 7385894) with its registered office at 81 Chancery Lane, London WC2A 1DD.

[For all our mental capacity resources, click here](#)