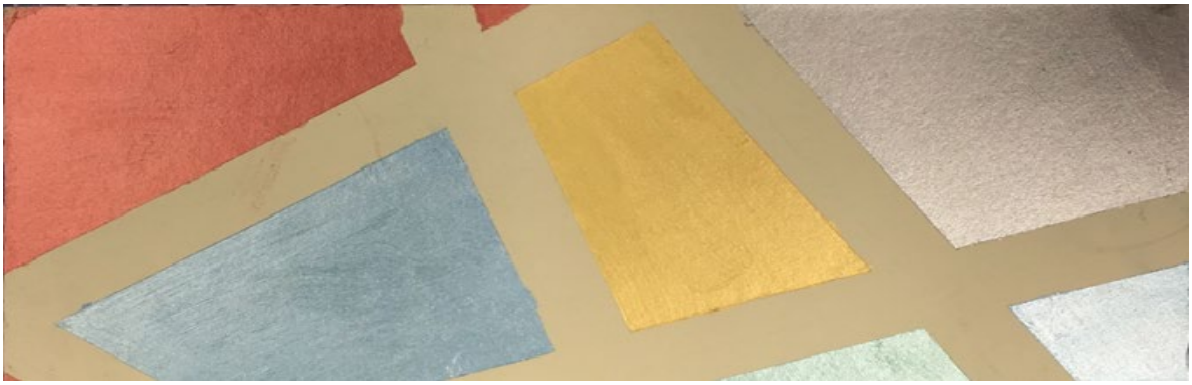
CHILDREN'S CAPACITY
December 2025 | Issue 156



Welcome to the December 2025 Mental Capacity Report. Highlights this month include:

(1) In the Health, Welfare and Deprivation of Liberty Report: holding the risk in medical treatment cases; capacity to marry under the spotlight; and mental health conditions, cancer investigation and capacity;

(2) In the Property and Affairs Report: the general costs rule in property and affairs cases under pressure, and a guest post on appointeeship;

(3) In the Practice and Procedure Report: fact-finding in the Court of Protection and recommendations about mediation in medical treatment disputes;

(4) In the Mental Health Matters Report: progress of the Mental Health Bill, community mental health services under pressure and a new website with Nearest Relative resources;

(5) In the Children's Capacity Report: brain stem death testing and procedural fairness, and children in complex situations at risk of deprivation of liberty;

(6) The Wider Context: suicide prevention and assisted dying / assisted suicide;

(7) In the Scotland Report: questionable guardianship.

We have also updated our unofficial update to the MCA / DoLS Codes of Practice, available 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.

We will be taking our usual break for the January report, but will be back in February; any urgent things requiring dissemination will be available via Alex's website. In the meantime, for a gentle provocation, you may care to watch this 'in conversation with' between Alex and Professor John Coggon as to whether mental capacity law is, in fact, law.

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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.

Contents

Brain stem death testing and the courts: procedural fairness, and the definitive diagnosis of death

Re A (A Child) [2025] EWCA Civ 1504 (Court of Appeal (King, Moylan and Phillips LJJ) and *Barts Health NHS Trust v MC & Anr* [2025] EWHC 3140 (Fam) (Family Division (Hayden J))

Other proceedings – family (public law)

Summary[1]

The issue of brain stem death testing (or, more formally, diagnosing death by neurological criteria) is one that has been before the courts no less than three times in the last month. The first case, *Re DT*, concerning an adult, focused on the question of where such testing should take place, as opposed to whether. The second two cases arose out of the awful situation facing a family whose 12 year old daughter, LS, suffered *an irreversible hypoxic ischaemic* brain injury in consequence of asphyxiation. As Hayden J described it in the most recent judgment, *Barts Health NHS Trust v MC & Anr* [2025] EWHC 3140 (Fam):

> *5. On her admission to Hospital A, LS was "neuroprotected" for 72 hours, to prevent secondary brain injury. She was reviewed by the neurosurgeons at Hospital A and the Paediatric Neurosurgeons at Great Ormond Street Hospital. Both neurosurgical teams concluded that LS had suffered a profound brain injury for which surgery was not an option. On clinical examination, LS's pupils remained fixed and dilated, she displayed no cough or gag reflex, and there were no signs of spontaneous breathing. An aEEG (amplitude integrated Electroencephalogram) was performed on 30th October 2025, which revealed an absence of any electrical activity. An EEG performed on 31st October 2025 was reported to be featureless and "does not show any discernible cortical rhythm consistent with diffuse cerebral dysfunction as seen in HIE".*
>
> *6. In the light of LS's flat clinical presentation, the clinical team considered that brain stem testing was indicated to determine whether LS had died. This, I am satisfied, was explained to LS's parents both by Dr. H, Paediatric Intensive Care Consultant, and Dr. G, Adult Intensive Care Consultant, on 30th October 2025. The plan was to perform the tests on Monday, 3rd November 2025. To ensure that the brain stem testing could be optimally performed, this was delayed to 4th November 2025 to enable LS to recover sufficiently from a chest infection she had developed following her admission to Hospital A.*

[1] Tor having been involved in the case, she has not contributed to this note.

> *7. In Guy's and St Thomas' NHS Foundation Trust v A & Ors [2022] EWHC 2250 (Fam), I encountered circumstances which raised real and important questions concerning the conditions necessary for the confirmation of death, most particularly in the context of babies under six months of age and those with open fontanelles. The Trust applied to the High Court for a declaration that A, who was two months of age, was dead. They also sought authorisation to withdraw his ventilation, ancillary care, and treatment. He had sustained a profound hypoxic ischaemic brain injury after a cardiac arrest that happened shortly after he was found limp in his cot with abnormal breathing. Brain stem tests had been conducted on four different dates, the last of which been performed by two doctors from a different Trust. Without exception, every test confirmed brain stem death. Over a week later, an experienced nurse on night duty discovered that the baby was beginning to breathe spontaneously.*
>
> *8. I was told in that case that the Code of Practice for the diagnosis and confirmation of death was being considered and reviewed at a national and an international level. This has now resulted in the Code of Practice 2025, which has been rigorously complied with in this case. The first set of clinical tests were carried out by Dr. D, Locum Consultant in Paediatric Intensive Care and Dr. E, Paediatric Specialty Registrar (ST6), and the second set of tests were performed by Dr. D and Dr. F, Clinical Fellow in Paediatric Intensive Care, with Dr. B, Consultant in Paediatric Intensive Care observing the testing and updating the assessment documentation. Both sets of clinical tests confirmed the absence of brain stem function and death by neurological criteria was diagnosed and confirmed at 4.45pm on 4th November 2025. LS's parents were informed of the outcome of the tests and were informed of the conclusions.*

Breaking off the narrative from Hayden J's judgment there, the parents did not agree to intensive care being withdrawn. Proceedings were brought by the Trust, on the basis that the case needed to be dealt with urgently. It was dealt by Judd J, in circumstances which gave rise to an appeal to the Court of Appeal on the basis that the proceedings had been so compressed as (in effect) to disable the parents from participating effectively in them. The Court of Appeal allowed the appeal,[2] agreeing that the proceedings had been procedurally unfair. It did not, however, accept that it had been necessary to join the child (identified at that point as 'R') as a party. Moylan LJ identified that:

> *38.* […] *it is agreed that, in respect of the current proceedings which are made pursuant to the High Court's inherent jurisdiction, there is no rule which requires R to be joined as a party and that the court has a discretion whether to do so. The Family Procedure Rules 2010 apply to "family proceedings" which include "all causes and matters … relating to … (ii) the exercise of the inherent jurisdiction of the High Court in respect of minors": s. 61 of and para. 3(b)(ii) of Schedule 1 to the Senior Courts Act 1981 and s. 75(3)(b) of the*

[2] For some odd reason the judgment is available on the Judiciary website, but does not appear to be on Bailii / the National Archives.

Courts Act 2003. The provisions in Part 16 of the FPR 2010 deal with the representation of children. They set out "when the court will make a child a party in family proceedings". Rule 16.2(1) provides: "(1) The court may make a child a party to proceedings if it considers it is in the best interests of the child to do so." If the court does make a child a party then, pursuant to rule 16.4, the court "must appoint a children's guardian for a child who is the subject of proceedings". There are a number of other provisions in Part 16 and PD 16A which deal with when a child should be joined as a party, the appointment of a guardian and the powers and duties of guardians.

39. In my view, the judge was entitled to decide that it was not necessary to join R as a party. As submitted by Ms Butler-Cole, the court was not engaged in a bests interest decision and there was no justification for joining R.

40. I do not accept Ms Dolan's submission that, as a matter of policy, a child should always be joined as a party and represented by a guardian when an application seeks a declaration of death. I agree with Ms Butler-Cole that it is difficult to see why, in accordance with the rules and more generally, it would be appropriate to join a child as a party and to appoint a guardian when the court is not engaged in a best interests decision as in the present case. Contrary to Ms Dolan's submissions, it is not necessary for a child to be joined and for a guardian to be appointed for the court to be able properly and fairly to determine the application and for the relevant rights and interests to be fairly and properly addressed. If the court requires additional assistance then the right route would be to seek such assistance from Cafcass as an advocate to the court although now that parents are entitled to non-merits and non-means tested legal aid, the need for this would seem to be significantly diminished.

The case was then listed before Hayden J for directions. At that point, he endorsed the instruction of a further expert to comment on the following:

"1. The validity of brain stem testing which has already taken place. and in particular whether the requirements in paediatric cases were satisfied that two clinicians be nominated to review the evidence of brain death prior to testing, that these same clinicians satisfied the requirements for expertise laid out by the Code.

2. The potential for recovery if ventilation was to continue for a further 2-3 weeks (or longer period).

3. The likelihood that the administration of steroids to [LS] could have impacted on the result of the brain stem tests.

4. Whether [LS]'s CRP markers are likely to have impacted on the results of the brain stem testing.

5. Provide an explanation for the movements [LS] has been making, i.e. What is the reason for the movements, and are they inconsistent with the death by the neurological criteria? Why are the movements happening now, but were not happening prior to the brain stem tests? [ML] and [MC] have videos of this movement, which you may find helpful to view.

6. Provide an explanation for the activity [ML] and [MC] observed on the scans, as outlined above, and the possibility that this was evidence of brain stem activity.

7. Whether there has been any improvement in [LS]'s condition and whether there has been increasing

somatic homeostatic stability, including the ability to thermoregulate. If so, does this show that the brain stem is functioning at least in part?"

As Hayden J continued:

25. The instructed expert was Dr. Simon Nadel, a Consultant in Paediatric Intensive Care and Visiting Professor in Paediatric Intensive Care Medicine at St. Mary's Hospital, London and Imperial College London. He arrived at the clear opinion that the brain stem testing carried out on 4th November 2025 was valid and demonstrated lack of brain stem reflexes, confirming brain stem death. Dr. Nadel had also been asked to consider movements in LS's fingers and limbs, observed by both the family and the treating clinicians. Dr. Nadel agreed with the view articulated by Dr. C, Consultant in Paediatric Neurology at the treating hospital, that the observed movements are non-purposeful, or "reflexive", as they have been called, and likely to be neuromuscular in origin. In his report dated 25th November 2025, Dr. Nadel stated the following, "a further full clinical evaluation of brain stem function may prove beneficial to reassure [LS]'s parents". He also went on to say that "if there continues to be doubt, I suggest to repeat the CT brain angiogram or carry out an MRI / MRA of the brain". It is necessary to state that extensive efforts have been made, with no fruition, to reassure LS's parents. Ultimately, for reasons that I will turn to below, their objection is predicated on their religious beliefs, which in MC's case, are uncompromising. I hope she will not take that phrase as a criticism, in her evidence she expressed her faith as requiring strict compliance.

26. The medical opinion as to brain stem death is, therefore, unanimous. Dr. Nadel was clear that the further clinical evaluation he discussed was not necessary to diagnose brain stem death but only required for the purpose of providing some reassurance for the parents. LS died on 4th November 2025. It is now 27th November 2025, she has been dead for over three weeks. In that period, her organs have been artificially maintained by invasive intubation, ventilation and other medications. There cannot be further protraction of this parlous situation. To do so would be to fail to respect the young girl LS was. A girl whom, her mother told me, "brought energy in to the room". It also fails to recognise the continuing distress this has caused, in particular, to the nursing team.

27. Mr Lawson, on behalf of the parents, has invited me to encourage Hospital A to repeat the CT brain angiogram. I do not take up that invitation. I have concluded that LS died. I am, therefore, not exercising a "best interests" jurisdiction. Nonetheless, as Dr. B emphasised, "this is about dignity". Undertaking a CT angiogram where the 'patient' is intubated and ventilated is, for obvious reasons, not a straightforward matter. Though there are not the same attendant risks here, given that brain stem death has occurred, it is inconceivable, to my mind, that an angiogram could be undertaken, the sole purpose of which would be to reassure the parents. That would compromise LS's dignity in death. In any event, having heard MC in evidence, I do not consider the scan would reassure her at all. Moreover, it is, again, inconceivable that the treating clinicians should be required

to undertake a process which both they and I would regard as unethical.

28. The parents explained their perspective in their statement in these terms:

> *"From our Islamic faith, even if someone is declared clinically dead, we believe that as long as the heart continues to beat, the soul remains attached to the body. In Islam, the soul is understood to be connected to the heart, not the brain, and therefore the heart and mind are regarded as separate matters. Accordingly, because [LS]'s heart was still beating, we firmly believed that her soul was still present and that she remained alive."*

29. In the witness box, MC reiterated this position. She also told me that she converted to Islam as a young woman. She had been brought up as a Protestant but told me that she had been very close to her Catholic grandmother, whose religion appears to have been a stronger influence upon her. MC told me that when she was younger, she considered other religions. She investigated Judaism, but felt it to be inaccessible to her, given the importance of the maternal line to Jewish identity. She also considered Buddhism, but that did not attract her. She discovered Islam, through colleagues at work, and told me of a point in her life when she was extremely low and how she was "rescued" by the Muslim faith. It was an experience that she described in transcendent, numinous and revelatory terms. Though she had been very controlled and measured in her evidence, it was only at this point that she became emotional and tearful. Her faith is manifestly important to her. She has studied the Quran and endeavoured to learn Arabic. She told me how important it was to her and to LS to have time to pray together. Her understanding of the medical evidence collides with the stronger pull of her faith.

30. MC told me that she had made enquiries with a hospital in another European country which might be able to accept and treat LS. She believed that their criteria for brain stem death were different from those in the UK. Ultimately, MC recognised that she had not been able to structure this into a choate plan to be considered by the Court.

Hayden J set out a crisp summary of the law:

31. As I have discussed above, death is a process, culminating in a diagnosis, thus, there is no statutory definition. The House of Lords in Airedale NHS Trust v Bland [1993] 1 AC 789 accepted the concept of brainstem death as legal death:

> *"In the eyes of the medical world and of the law a person is not clinically dead so long as the brain stem retains function." (per Lord Keith at para. 856C)*

32. Lord Goff expanded the point, at para. 863F-G:

> *"…as a result of developments in modern medical technology, doctors no longer associate death exclusively with breathing and heartbeat, and it has come to be accepted that death occurs when the brain, and in particular the brain stem, has been destroyed…"*

> *33. The legal position was confirmed by the Court of Appeal in Re M (Declaration of Death of Child) [2020] EWCA Civ 164 at para. 91:*
>
> > *"Firstly, as a matter of law, it is the case that brain stem death is established as the legal criteria in the United Kingdom by the House of Lords's decision in Bland. It is not, therefore, open to this court to contemplate a different test." (per Sir Andrew McFarlane (P))*
>
> *34. The President also emphasised, at para. 96, that once brain stem death has been diagnosed, the issue of best interests does not arise:*
>
> > *"Once a court is satisfied on the balance of probabilities that on the proper application of the 2008 Code (and where appropriate the 2015 Guidance), there has been brain stem death, there is no basis for a best interests analysis, nor is one appropriate. The court is not saying that it is in the best interest for the child to die but, rather that the child is already dead. The appropriate declaration is that the patient died at a particular time and on a particular date, without more."*

Ultimately, therefore, the answer was clear:

> *35. From the early stage of her admission to hospital, LS has shown no responses. The brain stem death tests have been thoroughly conducted and rigorously reviewed. I am left with no doubt, on this compelling evidence, that LS died on 4th November 2025 at 4.45pm and make Declarations to that effect.*
>
> *36. As a postscript, I would wish the clinical team and the nurses to know that I am very much aware of the reality of what has been asked of them since 4th November 2025. I have been told and understand how ethically challenging this period has been. It is also clear to me, having listened to Dr. B, that they have provided sensitive, gentle care and with real compassion. They have maintained LS's dignity, in death, in circumstances where it could easily have been lost. This requires to be recognised as a very considerable professional achievement.*

Comment

Hayden J took the opportunity to set out in some detail the new (2025) iteration of the AOMRC Code of Practice for the diagnosis and confirmation of death. He made a specific point of highlighting the Lay Summary, noting that:

> *12.* [it] *is, to my mind, an accessible document expressed in plain and sensitive language which does not compromise its intellectual rigour. It strikes me that, if it is not already the practice, parents or family members in these and similarly challenging circumstances should be made aware of it and directed to it by a member of the clinical team* […]. *It is perhaps the ubiquitous experience of lay people meeting with doctors that the questions they most want to ask occur to them only after the meetings have concluded when they have had a chance to absorb what they have been told. This lay summary of the Code of Practice anticipates many of the questions likely to be asked.*

More generally, it was helpful of the Court of Appeal to confirm that, in cases where a declaration of death is sought, since the issue before the court is not one of best interests, the child does not need to be joined. The same logic

must also apply to adults; it is to be hoped that the Official Solicitor would accept an invitation to act as advocate to the court in the circumstances envisaged by the Court of Appeal at paragraph 40 of the judgment. The Court of Appeal focused, however, very narrowly on the procedural requirements **if** the application is brought. It was notably reticent, however, as to **why** cases need to come to court where the tests have been carried out according to the AOMRC guidelines. That is an issue which may need to be addressed in due course.

Secure Children's Homes – guidance for young children

The Department of Education has published guidance entitled *Secure children's homes: how to place a child aged under 13*. This sets out the criteria for placing a child in a secure children's home (SCH) on welfare grounds, as well as the process that needs to be followed. In short, a local authority needs to get approval from the Secretary of State for Education to be able to place a child aged under 13 in a SCH. The guidance provides a step by step guide for seeking the Secretary of State's approval, including out of hours. Importantly, this Guidance specifies that a young person cannot be placed in secure accommodation without a court order for more than an aggregate of 72 hours in any period of 28 consecutive days. A local authority can however circumvent the need to go through the process of obtaining the Secretary of State's approval and then going to court, by simply making an application to the High Court.

Deprivation of liberty and complex situations

In a recent 'in conversation with,' Alex talks to Dr Susannah Bowyer, Deputy Director at Research in Practice, about the recent research paper published by Research in Practice and the National Children's Bureau (commissioned by DfE) entitled (snappily) *Improving the outcomes of looked-after children and young people in complex situations with multiple needs, at risk or subject to a Deprivation of Liberty*. Spoiler alert, they do not spend a great deal of time on the technicalities of deprivation of liberty, but instead think about the 'upstream' issues (they do, though, flag chapter 5 of the paper – the case-law briefing) written by Camilla Parker KC (Hon)).

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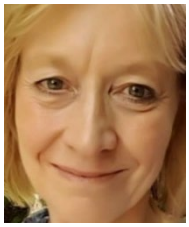

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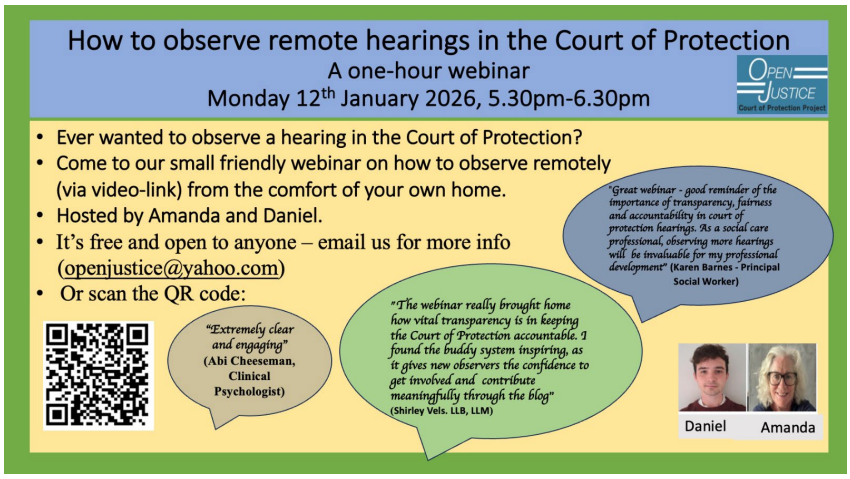
Conferences

Members of the Court of Protection team regularly present at seminars and webinars arranged both by Chambers and by others.

Alex also does 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.



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 January. 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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