

Welcome to the October 2023 Mental Capacity Report, which is much shorter than last month's blockbuster (to everyone's relief). Highlights this month include:

- (1) In the Health, Welfare and Deprivation of Liberty Report: Brain stem death before the courts and conveyancing;
- (2) In the Property and Affairs Report: the Powers of Attorney Act 2023 gets Royal Assent, and how it will change the Mental Capacity Act 2005;
- (3) In the Practice and Procedure Report: revised guidance for Accredited Legal Representatives and anonymisation of clinicians in cases involving the MCA 2005;
- (4) In the Wider Context Report: a revised online ADRT service and a revised clinical guide for staff working with autistic people and those with a learning disability, and our Irish correspondents highlight two specific aspects of the Assisted Decision-Making (Capacity) Act 2015;
- (5) In the Scotland Report: attorneys as executors.

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.

Editors

Alex Ruck Keene KC (Hon)
Victoria Butler-Cole KC
Neil Allen
Nicola Kohn
Katie Scott
Arianna Kelly
Nyasha Weinberg
Simon Edwards (P&A)

Scottish Contributors

Adrian Ward
Jill Stavert

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

Short note: brain stem death, an explainer of the law in England & Wales, and a question of consent

The case of Andy Casey sheds light again on the difficult question of diagnosing death by neurological criteria (“DNC”), and the wider question of what, in fact, it means to be dead. The first instance decision by Macdonald J can be found [here](#), and the decision of the Court of Appeal refusing permission to appeal [here](#). At the time of writing, it is not clear whether or not Mr Casey’s family sought to take the

case to Strasbourg, as they indicated they wished to do before the Court of Appeal, nor (if they did) what the Strasbourg court did in response.

For those who want to know more about it, this [explainer](#) by Tor and Ben Tankel is helpful; Alex's [review](#) of the recent book on the medico-legal development of neurological death in the UK by Dr Kartina Choong may also be helpful. And some may want to see the 2008 [Code of Practice](#) for the Diagnosis and Confirmation of Death by the Academy of Medical Royal Colleges, as well as the [2015 RCPC Code](#) relating to those under 2 months old (both currently under review).

One point to note is that it appears before the High Court and the Court of Appeal that there was an assumption that DNC testing requires the consent of a person with parental responsibility (if the individual is a child), or recourse to the Mental Capacity Act 2005 as a work-around for the inability of an adult suspected of being brain stem dead to give the necessary consent: see paragraph 31 of the first instance decision and paragraph 8 of the Court of Appeal decision. In this regard, it is perhaps of note that this is an assumption which was not necessarily shared by the Court of Appeal in the only previous case to reach it relating to DNC testing (the *Battersbee* case concerned the situation where it was not possible to carry out DNC testing). In *Manchester University NHS Foundation Trust v Namiq & Anor* [2020] EWHC 180 (Fam) (concerning a very young child, and hence in circumstances where both the 2008 Code and the 2015 Code were relevant), Lieven J was faced with the argument that:

[t]he DNC tests could only be carried out if the parents had given fully informed consent. He relies on Glass v UK to argue that the tests would be invalid without such consent. In my view this argument is wrong for a number of reasons. Firstly, the parents were aware that the tests were going to be carried out probably that day, as is shown by the transcript of the conversation with Dr E, and the Father did ultimately accept this. The transcript does not suggest that the Father or Mother said the tests should not go ahead. Further, the parents were fully informed as to the purpose of the tests, so in my view the issue about "informed" consent goes nowhere on the facts of the case. Secondly, I do not think there is any requirement for written consent from the parents, or for the information to be written down. There is no such requirement in the Code. Glass is dealing with a very different situation, where the issue was the withdrawal of certain treatment. It is not clear to me that consent would necessarily have to be given for a test at all. But, I do not have to decide that issue because the parents undoubtedly knew that the test was to be carried out, and knew what the test was about. Therefore they were given the appropriate information, and on the facts of the case their consent can be inferred from their conduct. Thirdly, and in any event, even if the tests should not have taken place because of lack of consent that does not mean that the outputs of the test would not be admissible before me. I am being asked to decide a factual question as to whether Midrar is dead, and lack of consent would not vitiate the evidence that goes to that issue (emphasis added)

Lieven's decision was challenged on this ground before the Court of Appeal, but the Court of Appeal [held](#) that "for reasons given by Lieven J, there is no merit in this point" (paragraph 68). And it is of note that the Canadian [position](#) in guidance published in May 2023 is that "consent for DNC testing should neither be required nor requested" – further explanation as to why this may be being given [here](#) (and note neither the 2008 nor the 2015 Codes mention the word 'consent,' with the words 'best interests' in the 2008 Code reserved for decisions about treatment of the patient, and not appearing in the 2015 Code at all). Put shortly, the argument that consent / a workaround for consent is not needed is that doctors should not be seeking to undertake DNC testing unless they properly

consider that the person is brain stem dead. And if a person is, indeed, brain stem dead, seeking consent by proxy (for a child) or thinking about their best interests for MCA purposes to testing is legally meaningless.

There is no doubt that involving those close to the person is hugely important, but we suggest that it is extremely important to know the basis upon which such involvement is taking place: seeking consent (in relation to a child), consulting or informing?

How we get there: conveyance plans in the Court of Protection

For those who have not already seen it, we strongly recommend reading Ian Brownhill's [blog](#) on 'conveyancing planning' before the Court of Protection on the Open Justice Court of Protection website. As Ian notes: "[a] 'conveyance plan' is, in the simplest sense, a plan which provides how a person will get from one place to another. However, conveyance is often one of the most complex areas legally and logistically in a case."

Multiple exclusion homelessness and mental capacity

Some may be interested to know of the launch of an NIHR-funded project (involving Alex) focusing on the assessment of the mental capacity of people who are experiencing multiple exclusion homelessness, a term used to capture the overlapping of a range of experiences associated with profound social exclusion, including not just homelessness but also institutional care, substance misuse, and 'street culture' activities. Factors such as poor mental health, addiction, and the effects of adverse childhood experiences in this population mean that capacity assessments under the Mental Capacity Act 2005 (MCA) can be particularly challenging. The research will explore and analyse health and social care practitioner approaches to mental capacity assessments with people experiencing multiple exclusion homelessness in England. Findings from mixed-methods research will inform the co-production of a revised and tested specialist assessment tool for this population. For more details, see [here](#).

PROPERTY AND AFFAIRS

Powers of Attorney Act 2023

Royal Assent was granted on 18 September 2023 to the [Powers of Attorney Bill](#) – now the Powers of Attorney Act 2023. When it comes into force (at a date yet to be set), it will make a number of substantial changes to – in particular – the procedure for making Lasting Powers of Attorney in England & Wales when it comes into force (the precise date for this is not yet known).

Despite the helpful [Explanatory Notes](#), the Bill is not an easy piece of legislation to read on a standalone basis. Alex has prepared an entirely unofficial [version of Schedule 1 to the Mental Capacity Act 2005](#) (providing for formalities relating to LPAs) as it will stand in due course.

For more details of the changes that it will make, and a walkthrough of the Act (recorded at an earlier stage of its life as a Bill, but in the same form, as no amendments were made as it went through Parliament), see Alex's website [here](#).

Law Commission Wills project

The Law Commission is relaunching its [project](#) on reforming the laws of wills. Following a consultation in 2017, the Commission paused completion of the project to undertake a review of the law concerning weddings/ The Commission has now re-started the wills project and aims to publish a supplementary consultation paper on 5 October 2023. Many will recall that the Law Commission proposed replacing the common test for testamentary capacity contained in *Banks v Goodfellow* with the statutory test contained in the MCA 2005, a step with which we would entirely agree.

PRACTICE AND PROCEDURE

Important guidance for accredited legal representatives

A must-read for ALRs, the Law Society has produced a updated [practice note](#) that provides detailed guidance on the role of an accredited legal representative in the Court of Protection. The note has been updated to reflect the benefit of experience since the ALR scheme came into effect.

This role involves specialist, approved solicitors personally appointed by the Court to fairly and competently represent P in the proceedings, and to discharge such other functions as the court may direct, whether or not P is a party. That responsibility cannot be delegated where the making of substantive decisions about the case is concerned. Interestingly, as some may not be aware, the guidance notes that there is no such scheme to appoint ALRs in property and affair cases.

The usual conundrum is whether, where P is joined as a party, they should be represented by a litigation friend or an ALR. The guidance sets out the relevant factors:

- whether there will be a need for expert or other evidence to be obtained and filed, or other material gathered, on P's behalf
- the nature and complexity of the case
- the likely range of issues

It adds the following considerations pointing to a situation where a litigation friend may be appropriate:

- where acting as both ALR and representative before the court is likely to mean that it is not possible to establish or maintain a working relationship with P
- where complex and novel points of law are likely to be involved
- where the proceedings are likely to involve fact-finding
- where the matter is contested with evidence to be given at a final hearing

As a result, *Re KL* [2022] EWCOP 24 confirms that it will “generally be unlikely” for the court to appoint an ALR in a case concerning a 16 or 17-year-old.

The guidance helpfully sets out the types of tasks that will be expected of an ALR, which are similar to that of the litigation friend. They have a right of audience. Court attendance is desirable, unless the ALR is available to give instructions to counsel without delay. They should meet P personally save in exceptional circumstances. In terms of the case they advance on P's behalf, the guidance says that they are not required to advance a case that accords with P's wishes if they consider that to do so would be unarguable (*Re NRA and others* [2015] EWCOP 59 at paragraph 144). But, in all cases, they must take all necessary steps to communicate P's wishes to the court upon the relevant issues.

Important information is provided on a whole range of other issues, including, for example, disclosure to P. It emphasises that an application for directions under rule 17.11 can always be made. A helpful summary of the usual rules regarding legal aid is also provided.

Short note: naming clinicians – a ‘cooling off’ period

We reported last month on the case of ST, in which Roberts J found that the 19 year old in question lacked capacity to decide upon her medical treatment because (we summarise) she could not believe her doctors when they told her that she was dying. ST did, in fact, die shortly after the judgment.¹ She can now be given her full name, as Sudiksha Thirumalesh, as can the treating Trust, University Hospitals Birmingham NHS Foundation Trust. In a judgment delivered on 29 September 2023, (*University Hospitals Birmingham NHS Foundation Trust v Thirumalesh & Ors* [2023] EWCOP 43),² Peel J endorsed the agreement of the parties as to the naming of Ms Thirumalesh (who, in light of that agreement had been named, in fact, following the hearing on 22 September), her families and the expert witnesses, and resolved the question of whether, in respect of the identification of the Trust, the hospital(s) attended by Ms Thirumalesh, and clinical / nursing staff, there should be an immediate discharge of the reporting restrictions, or a ‘cooling-off’ period of 8 weeks, as proposed by the Trust.

This required Peel J to consider the Article 8 and Article 10 ECHR rights in play, and the decision of the Court of Appeal in *Abbasi & Anor v Newcastle Upon Tyne Hospitals NHS Foundation Trust* [2023] EWCA Civ 331.

Peel J noted that:

36. The Trust points to its own evidence that relations between staff and parents during the care of ST was not always good. The witness statement in support expressly refers to "nurses and clinical staff". The parents made numerous complaints, which staff felt were unjustified. They "harassed" nurses and tried to interfere with care. Many clinical staff and nurses are extremely worried that they will now be named publicly, including in respect of criticism about care. The parents recorded a number of videos on mobile phones of staff working with ST, and staff are concerned that such videos may be released and might lead to adverse public reaction directed towards them. During the proceedings, media reporting, although anonymised, was perceived by staff to be negative, and two examples are attached to the statement. It is extremely difficult for staff to defend themselves against adverse reporting of this sort, and they would not want to comment publicly in any event. The witness statement prepared on behalf the Trust states that the author is "confident" that staff who cared for ST are likely to take time off work due to stress.

At paragraph 41, Peel J made clear that he did not accept that there was “insufficient evidence before me to weigh materially in the balance the Article 8 rights of clinicians and nursing staff. The witness statement to my mind sets out the anxieties clearly.” Nor did he accept, as was suggested by the family, that “each individual member of staff should apply separately to be anonymised by a Transparency Order or, at the very least, put in their own statement justifying being included within the Transparency Order. It is acceptable for a statement to be adduced in evidence which encompasses the views of all those

¹ We understand that her family intend to seek to appeal that decision, notwithstanding ST’s death.

² Tor was involved in this part of the case, but has not contributed to this note.

affected. That is what took place here. To require dozens of members of staff to set out their own cases would be impractical" (paragraph 42).

Importantly, Peel J also took the view that:

42. [...] when considering the evidence put forward on behalf of the Trust, I am entitled to place it in the context of the Court of Appeal's dicta at para 101 of *Abbasi*, quoted above:

"The Trusts place considerable reliance on the events surrounding the end-of-life proceedings of Charlie Gard and Alfie Evans. They certainly provide clear evidence of the real possibility of conduct impinging on the article 8 rights of staff before, during and immediately after end-of-life proceedings. It was part of the firm foundations for the making of RROs at the time. They do less to inform an assessment of article 8 risks associated with lifting the RROs at a later date."

In my judgment, the fact that improper conduct directed towards clinicians has taken place in other cases can in principle be taken into account in the intense balancing exercise, particularly where, as here, the court is considering transparency issues before, during or immediately after the proceedings. Such previous cases are informative of the potential risks run by hospital staff.

43. *In respect of the identification of clinicians, the family allege failings on the part of certain individuals, stating in terms that this amounted to negligence which led to the death of ST. Although the family, I accept, have no intention to take any steps which might lead to harassment of named staff, the harsh reality of modern methods of communications, particularly by social media, is that they will have no control over the narrative. The publicity generated by this case has been heated in some quarters. There is likely to be heightened interest in the coming days as a result of my intention that the restrictions on identifying ST and her family should be immediately lifted. If anonymisation of clinicians is lifted, the consequences are unpredictable, but there is in my judgment a risk that abuse and harassment may follow, particularly as they may be reported by the family as having given ST inadequate care. Were that to come to pass, I would regard it as a very considerable interference with their Article 8 rights. That risk is likely to be at its most acute in the next few weeks and I consider that there should be a "cooling off period" measured in weeks. That would be a proportionate interference with the family's and the media's Article 10 rights, given the potential interference with the clinical/nursing staff Article 8 rights.*

44. *This hearing is taking place only a matter of days after the tragic death of ST. That is factually different from the circumstances in both the *Abbasi* and *Haastrup* cases where, as para 1 of the Court of Appeal judgment says, "These appeals concern the principles to be applied when a court considers an application to vary or discharge a Reporting Restrictions Order ("RRO") **made long before in end-of-life proceedings in the High Court**" [emphasis added].*

45. *Where an application is heard long after the conclusion of proceedings, it is easy to see why there may be little justification for continuation of a Transparency Order. Media and public interest may have diminished. There may have been no improper conduct (of any nature, to any person) in the interim which would indicate a continuing concern about improper conduct towards as yet unnamed clinicians or other staff. The raw emotions upon or shortly after the death of a much-loved person may have dissipated.*

46. *But in this case, at this point in time, so close to the tragic death of ST, the likelihood is that interest in the circumstances leading to her death will be at its highest, and the risk of improper*

conduct is similarly at its highest. It seems to me that what is needed here is a relatively short elapse of time to allow matters to settle and reduce the risk of inappropriate secondary activity of the sort described by the Court of Appeal. I do not read the Court of Appeal as determining that the strength of the case for lifting such orders long after the end of proceedings would be the same as immediately after the end of the proceedings, and it seems to me that there is a very considerable difference between the circumstances before the Court of Appeal and the circumstances here.

47. *It is further submitted on behalf of the family that the potential clinical negligence claims which they are exploring demand an immediate lifting of the Transparency Order in respect of identifying individual doctors. Counsel relies on para 114 of Abbasi in which it was said that:*

"Those involved in clinical negligence claims resulting in death would need a factually quite exceptional case to secure anonymity in civil proceedings or at an inquest touching the death".

48. *However, in this case clinical negligence proceedings are simply being considered. Unsurprisingly, given that only a few days have passed since death, no claim has been instituted. I understand that the family, sensibly, intend to take time to consider their position. It is accepted that were such proceedings to be instituted before discharge of the order anonymising clinicians (or were formal complaints to regulators or the like to be brought), it would be appropriate to vary the order permitting the lifting of restrictions for the purpose of such proceedings.*

Peel J therefore concluded that he should have in place the transparency order insofar as it related to the non-identification of clinicians/nursing staff for a limited period of time before automatic discharge, considering 8 weeks to be a "proportionate and appropriate" timescale. He made clear at paragraph 49 that, "[f]or the avoidance of doubt, this does not prevent the family from discussing or reporting openly their perception of failings by the Trust and its staff, but they are not permitted to identify any treating clinicians/nursing staff as part of any such discussions or reporting" (paragraph 49).

Peel J declined to require that the order identify each member of staff within these two categories, as was commended in *Abbasi*. He noted at paragraph 51 that "[t]he numbers would run into dozens, and there is a risk of not capturing all the relevant names. At the risk of repetition, my approach might have been different if this application was being considered long after the event; by then, it might be easier to identify if any particular individuals or individuals were at greater risk." He also provided that any videos or photographs which the family may have taken of clinical and nursing staff should not be published, as they could lead to identification of individual clinicians/nurses. Again, these would be discharged in 8 weeks, although he noted that there might be separate written agreements in place between the family and the Trust which would in any event govern publication.

As regards, the Trust, Peel J noted at paragraph 53 that "once ST is identified, it will swiftly be known where she lived, and the Trust will be easily identifiable. To retain the provisions of the Transparency Order in respect of the Trust would be futile." However, he continued:

54. *[...] to identify specific hospitals attended by ST would carry a risk of jigsaw identification of the clinicians. I accept that as there are only four hospitals run by the Trust, there is inevitably a risk of identification even if a specific hospital is not named, but (i) the order will prevent naming of clinicians/nursing staff, and (ii) the fact that a particular person may know of the identity of the Trust does not lead automatically to identification of the particular clinicians who treated a particular patient at a particular time.*

Court of Protection and LPA statistics April – June 2023

The most recent set of statistics has now been published by the MoJ, showing, in headline terms:

- There were 1,432 applications relating to deprivation of liberty made in the most recent quarter, which is a decrease of 2% on the number made in the same quarter in 2022. Of these applications, 142 were for s.16 orders, 470 under s.21A and 820 for 'community DoL' orders. There was an increase by 162% in the orders made for deprivation of liberty over the same period from 648 to 1,698; although the statistics do not make this clear, it is likely that this is in large part down to a sustained push by the court to seek to clear the 'community DoL' backlog;
- In April to June 2023, there were 7,746 applications made under the MCA 2005, down by 9% on the equivalent quarter in 2022 (8,498 applications). Of those, 30% related to applications for appointment of a property and affairs deputy. There were 16,349 orders made under the MCA 2005, up by 45% on the same quarter in 2022. Of those, 39% related to orders by an existing deputy or registered attorney.
- There were 7,746 applications made in April to June 2023, down by 9%. During the same period there were 16,349 orders made, up by 45% - the highest quarterly volume for orders since the start of the series.
- In April to June 2023, there were 275,569 LPAs registered, the highest in its series and up 43% compared to the equivalent quarter in 2022.

THE WIDER CONTEXT

“Proportional assessments,” remote assessments, the Care Act and the MCA – an update

We noted last month the [guidance](#) on carrying out proportionate assessments under the Care Act 2014 issued by the chief social worker for adults, Lyn Romeo, and principal social workers have issued. It has been updated to make clear that it is legitimate in some circumstances to carry out assessments under the MCA 2005 without seeing the person:

Mental capacity assessments should normally be completed in person, but it may be appropriate to carry out the assessment remotely if, for example, it is not possible to visit the person.

The principles of the Mental Capacity Act 2005 must underpin assessments where there is a proper reason to doubt that the person has the capacity to make the decision in question. Most deprivation of liberty safeguards assessments should be face to face in order to, for example, meet any communication needs of the person.

An important principle of the Mental Capacity Act 2005 is that it must be assumed that the person has capacity unless it is established that they lack capacity. Assuming capacity, however, should not be used as a reason for not assessing capacity in relation to a decision. There should always be an assessment where there is a proper reason to doubt a person’s capacity to make a decision.

This also gives an opportunity to note that Lyn Romeo CBE will be leaving her role in January 2024, having served since January 2013 as the first chief social worker for adults. We wish her well, and thank her for a huge amount of often unsung and frequently thankless work that she has done in post.

Free service to create advance decisions from Compassion in Dying, and advance decisions in the South Asian community

The charity Compassion in Dying has updated their free online service to assist people who wish to [make advance decision](#) to refuse treatment. It is available only to people who have capacity, are 18 or over and live in the UK. The service takes people through the form step-by-step (people can also save the document and return to it if they wish), and creates a document that people can execute (this document would need to be signed and witnessed to be valid). People would also be responsible for sharing copies of the document with their GP or other health provider, and for making family members aware of the fact that they have made an advance decision. The service also has a [template form](#) people can download and prepare by hand, or they can [order the form by post](#) to be sent to them if they do not have access to a printer.

Importantly, Compassion in Dying have made the underlying machinery freely available, so that it can be [‘white-labelled’](#) by others, whether that be another charity or a health body working to develop electronic end-of-life records.

Separately, Compassion in Dying has launched a new report on [‘Advance Care Planning with people from South Asian Communities’](#) in partnership with Subco Trust and Bristol University’s Good Grief Connects project. The South Asian people involved in the project made clear that they face inequities in access to advance care planning and support towards the end of life. People faced significant

challenges when talking to healthcare professionals, finding and understanding information, making treatment and care decisions and accessing support.

The experiences Subco Trust members shared demonstrated a clear need to allow people to consider and make informed decisions about planning for the end of their life. Meaningful attention and investment at both a national and local level is needed to provide culturally and linguistically appropriate information and support.

Clinical guide for front line staff to support the management of patients with a learning disability and autistic people

NHS England has published new [guidance](#) (updated from predecessor guidance in 2020) for staff on caring for patients with a learning disability or autism; the guidance specifically notes that it is relevant for [all](#) clinical specialities, rather than simply those providing care relating to learning disabilities or autism. The guide is also available in an [easy-read format](#).

The guidance emphasises that approximately 2.5% of people in England have a learning disability, and approximately 1-1.7% of the population has autism. It notes that people with a learning disability have higher rates of death from avoidance causes and tend to die at a younger age, and there is also evidence of premature mortality for people with autism. It highlights the following 'key points' which should be addressed when assessing or treating a person with a learning disability or autism:

***Be aware of diagnostic overshadowing:** This occurs when the symptoms arising from physical or mental ill health are misattributed to a person's learning disability or autism leading to delayed diagnosis or treatment. People with a learning disability and autistic people have the same illnesses as everyone else, but the way that they respond to or communicate their symptoms may be different and not obvious.*

***Pay attention to healthcare passports:** Some people with a learning disability and some autistic people have a healthcare passport giving information about the person and their health needs, preferred method of communication and other preferences. Ask the person or their accompanying carer if they have one of these.*

***Ensure that clinical decisions around care and access to treatment are made on an individual basis:** People should not have a DNACPR (do not attempt cardiopulmonary resuscitation) recorded on their clinical record simply because they have a learning disability or are autistic. Every person has individual needs and preferences which must be taken account of, and they should always have high quality standards of care. It is also important not to make generalised judgements or assumptions about people's vulnerability or frailty based on their dependence on others for support in daily living.*

***Listen to parents and carers:** Families and carers have a wealth of information about the individual and how their health has been, including any comorbidities and the medication that the person is taking. Listen to them as well as the person you are caring for. They know the person well and how to look after them when they are not in hospital. They also know how the person's current behaviour may differ from usual, as an indication that they are unwell. The family or carer may have short videos of the person to give you an idea of their usual self. Remember that the carer they come into hospital with may not be their usual carer at this unusual time. You may wish to talk to their*

usual carer as soon as is practicable.

Make reasonable adjustments: It is a legal requirement to make reasonable adjustments to care for people with a disability under the Equality Act (2010). Getting the reasonable adjustments right is important to help you make the correct diagnostic and treatment decisions for an individual. You can ask the person and their carer or family member what reasonable adjustments should be made. Adjustments aim to remove barriers, do things in a different way, or to provide something additional to enable a person to receive the assessment and treatment they need. Possible examples include allocating a clinician by gender, taking blood samples by thumb prick rather than needle, providing a quiet space to see the patient away from excess noise and activity.

Communication: Communicate with and try to understand the person you are caring for. Check with the person themselves, their family member or carer or in their hospital or communication passport for the best way to achieve this. Use simple, clear language, avoiding medical terms and 'jargon' wherever possible. Some people may be non-verbal and unable to tell you how they feel. Pictures may be a useful way of communicating with some people, but not all.

Understanding behavioural responses to illness, pain and discomfort: A person with a learning disability and some autistic people may not be able to articulate their response to pain in the expected way: for example, they may say that they have a pain in their stomach when the pain is not there; may say the pain is less acute than you would anticipate; or not say they are in pain when they are. Some may feel pain in a different way or respond to it differently: for example, by displaying challenging behaviour; laughing or crying; trying to hurt themselves; or equally may become withdrawn or quiet. People who use a wheelchair may have chronic pain. Understanding what is 'normal' for that person by talking to them, their family and carers, is crucial to helping with assessment and diagnosis. You can use pictures to help establish whether a person is in pain and where that pain is.

Mental Capacity Act: People with a learning disability and autistic people should be assumed to have capacity in line with the principles of the Mental Capacity Act. Assess their capacity to make a decision about their treatment or care in line with the person's communication abilities and needs and follow the principle of the Mental Capacity Act in making appropriate efforts and adjustment to enable decision making wherever possible. Remember that capacity is time and decision-specific. Refer to the MCA Code of Practice for guidance.

Ask for specialist support and advice if necessary: Your hospital learning disability team or liaison nurse can help you with issues of communication, reasonable adjustments, and assessment of pain. You may also want to make contact with your local community learning disability team if your Trust does not have a learning disability liaison nurse.

Training on how to support people with a learning disability and autistic people: The Oliver McGowan Mandatory Training on Learning Disability and Autism is the government's preferred and recommended training for health and social care staff. Access the e:learning on: [The Oliver McGowan Mandatory Training on Learning Disability and Autism](#).

Mental wellbeing and emotional distress: It is estimated that 40% of people with a learning disability experience mental health problems ([Mental health problems in people with learning disabilities: prevention, assessment and management](#)) and research suggests autistic people may be more likely to experience depression than non-autistic people ([Depression \(autism.org.uk\)](#)). Change in routine can have a big effect on people's emotional and mental

wellbeing. A hospital setting may make people with a learning disability and autistic people more anxious or lead to adverse behaviours, such as hurting other people, hurting themselves or damaging property. Do not assume that this is an indication of mental illness and do your best to work with the person who is unwell, their carer or family member to find out how best to keep them calm and relaxed.

Disagreements about the care of critically ill children

The Nuffield Council on Bioethics has published the report of the review it was commissioned in December 2022 to carry out by the Secretary of State for Health and Social Care, on the causes of disagreements between parents and healthcare teams about the care of critically ill children (i.e. children unwell enough to be treated in intensive care). Unsurprisingly they found that one of the key causes of disagreements was communication issues. Mismatched expectations (i.e. about what is medically possible, what medical information is or is not significant, or about what is involved in the provision of palliative care) was also found to be very influential on the development of disagreements. Conversely, they found that where healthcare professionals had built relationships with parents, had understood their needs and communicated accordingly, this had a positive impact on parents. Equally they found that where uncertainty was communicated honestly, this was seen to have a positive impact on relationships and the building of trust between parents and healthcare professionals.

They made a number of recommendations about resolving disputes, including that:

- Guidance should be produced for clinical ethics committees (CEC) on how to ensure that parents', and where appropriate children's, views are taken into account in CEC discussions and that parents are supported to provide input to CEC meetings.
- NHS trusts in England should inform families within three calendar days of taking the decision to initiate court proceedings in order to give them sufficient time to seek independent legal advice and collate necessary information to disclose to the court.

The report was lukewarm on mediation between parents and healthcare professionals, finding that it can be helpful in some situations to facilitate open conversations, but that there is no current evidence to support mandating its use in every case or in disagreements that would otherwise go to court.

It is of interest to note that the report does not recommend a change in the 'best interests' test applied by the courts in cases concerning children. It is also perhaps important to note two developments that the report was not able to incorporate in what is otherwise an extremely comprehensive review of a very complicated area. The first is the coming into force of the removal of means-testing for parents involved in cases concerning life-sustaining treatment of children, with effect from 3 August 2023 (rather earlier than the report authors had feared). The second is that the Supreme Court have agreed to hear the appeal by the Trusts involved in the *Abbasi* and *Haastrup* cases in relation to reporting restrictions relating to medical professionals, an issue identified as being one of concern to professionals in the report.

Deprivation of liberty and children

The Nuffield Family Justice Observatory has published its key findings from 12 months of research at the national deprivation of liberty court. It makes for sobering reading. They found that:

- 1,249 children had been subject to a Deprivation of Liberty (DoL) order and between July 2022 and March 2023, there were almost 10 times as many applications to deprive children of their liberty under the inherent jurisdiction than there were applications for secure accommodation orders.
- The children have multiple and complex needs, including mental health problems, behavioural and emotional difficulties, and difficulties with education – which they are not receiving adequate support for.
- Their behaviours are often associated with experiences of early and ongoing childhood adversity (such as abuse and neglect, but also poverty and racism) and complex trauma.
- While it is often intended as a temporary measure, many children will continue to have their liberty deprived for many months while living in what are often unsuitable – and illegal – placements far from home and their communities. The restrictions imposed on them are often severe and multiple.

The report considered the reason why there has been such a huge increase in the number of applications. It was multifactorial, including a reduction in places in children's secure homes and in child mental health beds, as well as an increase in the number of children in care and in the complexity of their presenting needs. For lawyers who do this kind of work, the finding that children have limited opportunity to participate or have their voices heard in deprivation of liberty proceedings is something that must be addressed as a matter of urgency.

Forced marriages and non-recognition

For those who want to continue to track through the complexities of forced marriages and non-recognition, we recommend the [paper](#) by Sir Nicholas Mostyn responding to the decision of the Court of Appeal in *Re SA (Declaration of Non-Recognition of Marriage)* [2023] EWCA Civ 1003 we covered in brief in our last issue.

Australian Disability Royal Commission reports

The Australian Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, established in 2019, has reported, making 222 recommendations on how to improve laws, policies, structures and practices to ensure a more inclusive and just society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation.

The Final Report consists of 12 Volumes plus an additional introductory volume, which includes the Chair's foreword, the Commission's vision for an inclusive Australia, an executive summary and the full list of recommendations. All volumes of the Final Report are available in various accessible formats [here](#). The Royal Commission has also published *A brief Guide to the Final Report*. This guide explains how information is organised in the Final report. It is for a broad audience including people with disability, their families and carers, other members of the Australian community, disability advocates, service providers and people looking to quickly find the information they need.

Additionally, the Royal Commission has published a brochure called *Listening to First Nations people with disability*. This brochure describes what the Commission heard from First Nations people with disability and their families and communities about the issues and challenges they face. It also describes some of the changes needed to create an Australia where First Nations people with disability are included.

Whilst the focus of the Report is on Australia, there is much that those working in other jurisdictions can – and should – draw upon.

IRELAND³

Co-Decision-Making Agreements

With very little in the way of capacity law happening over the long vacation, we thought this a perfect opportunity to highlight one of the rather unique features of the newly commenced capacity legislation in Ireland, namely a co-decision-making agreement. This agreement sits above a decision-making assistance agreement which offers simply assistance to the appointer, and beneath a decision-making representation order which is a relationship of agency following court appointment. A co-decision-making agreement is a mid-level decision-support mechanism under the Assisted Decision-Making (Capacity) Act 2015. It can be made either at the behest of a person whose capacity is or may soon be in question, or following a declaration that the person lacks capacity unless they have such an agreement. The core feature is that decisions must be made jointly by the appointer and the co-decision-maker.

Criteria for Co-Decision-Makers

A co-decision-maker must adhere to the appointer's wishes but can refuse to sign a document if it could lead to serious harm, and their authority is limited to decisions explicitly outlined in the agreement. A person is deemed suitable to act as a co-decision-maker if they meet two criteria: (i) they must be a relative or friend with whom the appointer has a trusting relationship, established through significant personal contact over time; and (ii) they must be capable of fulfilling the roles and responsibilities as outlined in the co-decision-making agreement and the legislation. An appointer can appoint multiple co-decision-makers, but with limitations; within a single agreement, only one co-decision-maker can be appointed.

Court Declarations and Applications

In a capacity application or a discharge from wardship application, the applicant can seek a court declaration under section 37(1)(a) or section 55(1)(b)(i) that the relevant person lacks the capacity to make certain decisions unless assisted by a suitable co-decision-maker. If such a declaration is made, the relevant person is given time to register a co-decision-making agreement. Alternatively, the process for creating a co-decision-making agreement begins with the appointer submitting an 'Application to Register a Co-Decision-Making Agreement' form to the Decision Support Service.

³ Prepared by our Irish correspondents, Emma Slattery BL and Henry Minogue BL.

Application Review Process

Upon receiving the application, the Decision Support Service reviews it and sends back a draft agreement, a capacity statement, character references, declarations, and notice forms. A capacity report confirms the appointer's capacity to enter into the agreement. Two character references are also required for the co-decision-maker, and both parties must sign declarations that are witnessed by two individuals.

Notification and Objections

The appointer and co-decision-maker are required to notify specific parties, such as spouses or adult children. Objections to the registration can be raised within five weeks on various grounds, including the appointer's lack of capacity or the co-decision-maker's unsuitability. An application to register a co-decision-making agreement must be submitted within five weeks of signing the agreement and is accompanied by a €90 fee. The Director either registers the agreement if all criteria are met or refuses registration, in which case the applicants must notify specific parties such as spouses or adult children, and an appeal can be filed within 21 days.

Legal Implications of Registration

Once a co-decision-making agreement is registered, decisions made within its scope are binding and cannot be challenged based on the appointer's capacity. For decisions requiring the signature of documents, both the appointer and the co-decision-maker must sign them, with exceptions made if the appointer is unable to sign. Importantly, a joint decision does not equate to joint liability. The Director of the Decision Support Service is responsible for establishing and maintaining a register of these agreements. Various professionals and public bodies, including medical practitioners and legal professionals, have the right to inspect this register. Authenticated copies can be issued by the Director for a fee and serve as evidence of the agreement's content and any variations.

Remuneration, Annual Reviews and Codes of Practice

Co-decision-makers are entitled to reimbursement for fair and reasonable costs and expenses incurred while performing their duties, although they are not entitled to remuneration. These costs must be evidenced and reported to the Director. Co-decision-makers are also required to adhere to relevant codes of practice. The Director reviews each registered co-decision-making agreement annually. These reviews involve consultations with the appointer, co-decision-maker, and any visitors on behalf of the Director who have had contact with them. A capacity report confirming the appointer's continued need for decision-making support is also required.

Variations and Revocations

Both the appointer and the co-decision-maker may mutually vary the terms of a co-decision-making agreement, subject to specific signing and witnessing requirements. A varied agreement must be registered, accompanied by a fee of €90 and supporting documents, including a capacity report confirming the appointer's capacity. The application for such a variation cannot be made earlier than six months from the initial registration and subsequent applications must be at intervals of no less than 12 months. In addition, a co-decision-making agreement can be either totally or partially revoked by

either party or both.

Conclusion

While it remains to be seen what the uptake of co-decision-making agreements will be, co-decision-making agreements offer a useful middle ground for people who require some form of decision-making support, without the requirement to resort to substitute decision-making.

Emma Slattery

Decision Support Service (DSS) and Codes of Practice

The Decision Support Service ('DSS') is the statutory service established by the Assisted Decision-Making (Capacity) Act 2015 (as amended) ('the Act'). The DSS provides an essential service for people who face difficulties in exercising their decision-making capacity.

In the run up to the initiation of the Act, and over the course of 2022, the DSS implemented a public consultation process on several of the draft codes of practice on the Assisted Decision-Making (Capacity) Act 2015.

Following ministerial approval, on the 24th of April 2023 the Codes of Practice were published in tandem with the commencement of the Act. There were 13 Codes of Practice were published by the DSS, providing guidance as to functions and responsibilities under the Assisted Decision-Making (Capacity) Act 2015 (as amended) (See [link here](#)).

While similar in function to the Mental Capacity Act 2005 Code of Practice, covering England and Wales, the position of Codes of Practice in Ireland goes into much more granular detail for each distinct area of support underlined in the Act.

Codes of Practice

These 13 Codes of Practice can be broken down into three categories, the first gives general guidance to any person involved with a relevant person, especially when the person must make an important decision. The other five are for the various tiers of decision supporters and health care representatives. The remaining seven pertain to specific professionals when working with a relevant person, e.g., general visitors, legal practitioners, financial professionals etc.

The codes of practice are generally drafted with the same emphasis and wordings, but for this edition of the Report, we will consider guidance given to legal practitioners.

Code of Practice for Legal Practitioners

The code for legal practitioners covers many various areas, such as:

- Assessing capacity for a specific decision;
- Advising a client on decision support arrangements;
- Record keeping;

- Interacting with the Decision Support Service; and
- Court matters, etc.

An example of such guidance of the code for legal practitioners' is directions around interacting with the relevant person, which is given in the following terms⁴:

When interacting with a person who needs to make a decision, you must presume they have capacity to make that decision at the time it needs to be made. A relevant person must not be considered unable to make a decision until all such steps set out in this code and all practical steps have been taken to help them to make that decision.

The code also underlines the responsibilities of legal practitioners when they hold a belief that the relevant person's decision supporter, is not performing their duties to the required level.

Where you believe [the practitioner] that a relevant person's decision supporter is not performing their functions appropriately or is acting beyond the scope of their authority, you may make a complaint to the Decision Support Service. This includes complaints about attorneys appointed under the Powers of Attorney Act 1996 in addition to all decision supporters appointed under the 2015 Act.

Of note to practitioners, the section discussing taking instructions from a decision supporter is of particular importance:

A decision supporter may seek to instruct you in relation to court proceedings involving or on behalf of a relevant person. Court proceedings may be included as a property and affairs decision within a decision support arrangement. You should check the authority of the decision supporter to take this action on behalf of the relevant person, as described in section 3.2. A decision supporter may only instruct you if such a decision is within the scope of the decision support arrangement.

Conclusion

Overall, the codes are very discrete and condensed documents, most of which vary from 22-25 pages in length, and are formulated in plain English. In addition, the DSS have compiled several user friendly walk-through videos available on YouTube for consultation (See Playlist [Link here](#)).

Henry Minogue

⁴ This is also in line with the 'guiding principles' section of the Act.

SCOTLAND

The competence of appointment of an executor *qua* attorney

Mr Rae died leaving a Will under which his widow, Mrs Rae, was sole beneficiary, and in which he appointed two executors. Both executors predeceased him. Mrs Rae would have been entitled to be confirmed executrix, either in a nominate capacity by virtue of section 3 of The Executors (Scotland) Act 1900, or in a dative capacity *qua* relict of the deceased, except that she was considered to be incapable of competently acting as such. Mrs Rae had however appointed a Ms Gordon to be her attorney, with powers held to be adequate to enable her to seek Confirmation as Mr Rae's executrix. It is perhaps surprising that more than 22 years after Part 2 of the Adults with Incapacity (Scotland) Act 2000 ("the 2000 Act") came into force, there should have been any doubt about Ms Gordon's entitlement to be confirmed executrix-dative *qua* attorney of Mrs Rae. It is helpful, however, that on 1st September 2023 Sheriff P Mann, sitting at Aberdeen Sheriff Court, granted Ms Gordon's petition to be so appointed [*Gordon, Petitioner*, 2023 S.L.T. (Sh Ct) 187]. This decision follows, after a significant time lag, the decision in *B's Guardian, Minuter* (Sh Ct Edinburgh, 21 July 2010, unreported, 2010 G.W.D. 33-690) that in similar circumstances it was competent to appoint a guardian as executor. Acting for the Minuter in that case was R A S MacLeod (then a solicitor, now an advocate). While it might be seen as unusual for one commentator to refer to another on the same case, it is significant that Mr MacLeod has now provided some helpfully researched background in his article "The appointment of an attorney as an executor", 2023 SLT (News) 135. Sheriff Mann's decision is commendably succinct, extending to three columns. I recommend that Mr MacLeod's article be read in conjunction with it.

What was the difficulty? The perceived difficulty was an assertion at paragraph 8-43 of the current edition (the 9th edition) of *Currie on Confirmation of Executors* that: "The power of attorney of a UK resident person will never enable the attorney to apply for confirmation on behalf of the *incapax*". Currie bases that assertion on the judgment of Sheriff Macvicar in the case of *Leishman*, unreported December 17, 1980. However, Sheriff Mann made a distinction between cases where the granter of the power of attorney is at time of application to be appointed capable, or alternatively incapable: "*Leishman* does not appear to me to be authority for the proposition that it is incompetent to appoint an attorney of an individual who is *incapax*. I am inclined to disagree with *Currie* on this matter so far as it concerns an *incapax*. I take no exception to the proposition that it is incompetent to appoint an attorney in place of a UK resident who is *capax*."

He could have added that in 1980, when *Leishman* was decided, the attorney would only have had power to act if the granter were capable at the time. The general view was that powers of attorney ceased to have effect upon the incapacity of the granter. That remained the position until it was reversed by the Law Reform (Miscellaneous Provisions) (Scotland) Act 1990, that regime having lasted only until the relevant provisions of the 2000 Act came into force in 2000. In other words, *Leishman* cannot have been authority after 1990 for the above quotation from *Currie*. More generally, one would have to say that it would be necessary to be cautious about the relevance of a decision made over 50 years ago during the first of three successive power of attorney regimes, each fundamentally different from its predecessor; and that any such reliance would require to be clearly justified. Interestingly, Mr MacLeod in his article points out that in this regard: "The commentary at p92 of the 7th edition of *Currie* is more permissive than that in the current edition".

Sheriff Mann in fact gave two cogent reasons why the attorney should be appointed. He said that: "I can see no reason in principle why it should not be equally as competent to appoint an attorney as to appoint a guardian or the holder of an intervention order to the office of executor-dative *qua* such in these circumstances. All such representative parties are subject to the terms of the Adults with Incapacity (Scotland) Act 2000 (at least where the attorney is appointed after the coming into force of that Act). All are thus subject to supervisory powers of the public guardian and the court. All would require to find caution. One could argue that an attorney appointed by the person with the right to be appointed executor, and in whom that person has placed his trust, has a better claim to be appointed than a person appointed by the court. In many, if not most, cases the person who might be appointed attorney might also be the person who would be appointed guardian or intervener."

He went further by referring to the public interest: "It seems to me that there is a compelling public interest to ensure that the estates of deceased persons should be administered with the least possible delay and with the least possible expense. In a case where there is an attorney in place for an *incapax* individual with the right to be appointed executor, to insist that a guardian be appointed as a precursor to the appointment of an executor-dative does not satisfy that public interest." Mr MacLeod developed that further by pointing out that to insist on appointment of a guardian, where an attorney already had relevant powers, would contravene the section 1 principles of the 2000 Act, particularly the requirement that any intervention should be the least restrictive option in relation to the freedom of the adult (section 1(3)) and the mandatory requirement to take account of the present and past wishes and feelings of the adult (section 1(4)). One might add the obligation to comply with the European Convention on Human Rights: to disregard Mrs Rae's choice of who should act for her in the event of her own incapacity, and to insist upon a burdensome additional procedure which would not have been required but for her incapacity, would appear to contravene the right for respect to private and family life in Article 8, and in association with that to contravene the prohibition of discrimination under Article 14. That position is reinforced by (a) Principle 1 of Council of Europe Ministerial Recommendation CM/Rec. (2009)11 that states should promote self-determination for capable adults in the event of their future incapacity by means of continuing powers of attorney and advance directives, and that in accordance with the principles of self-determination and subsidiarity, states should consider giving those methods priority over other measures of protection; and (b) interpreting both the 2000 Act and those 2009 Principles by reference to the UN Convention on the Rights of Persons with Disabilities. Many of the provisions of the UN Convention are relevant, including the prohibition of "all discrimination on the basis of disability" in Article 5 and the requirement of Article 12.4 that the will and preferences of the adult be respected.

Adrian D Ward

Editors and contributors

Alex Ruck Keene KC (Hon): alex.ruckkeene@39essex.com

Alex has been in cases involving the MCA 2005 at all levels up to and including the Supreme Court and the European Court of Human Rights. He also writes extensively, has numerous academic affiliations, including as Visiting Professor at King’s College London, and created the website www.mentalcapacitylawandpolicy.org.uk. To view full CV click [here](#).



Victoria Butler-Cole KC: 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. She is Vice-Chair of the Court of Protection Bar Association and a member of the Nuffield Council on Bioethics. To view full CV click [here](#).



Neil Allen: neil.allen@39essex.com

Neil has particular interests in ECHR/CRPD human rights, mental health and incapacity law and mainly practises in the Court of Protection and Upper Tribunal. Also a Senior Lecturer at Manchester University and Clinical Lead of its Legal Advice Centre, he teaches students in these fields, and trains health, social care and legal professionals. When time permits, Neil publishes in academic books and journals and created the website www.lpslaw.co.uk. To view full CV click [here](#).



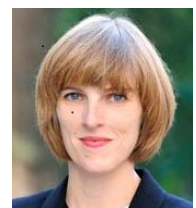
Arianna Kelly: Arianna.kelly@39essex.com

Arianna practices in mental capacity, community care, mental health law and inquests. Arianna acts in a range of Court of Protection matters including welfare, property and affairs, serious medical treatment and in inherent jurisdiction matters. Arianna works extensively in the field of community care. She is a contributor to Court of Protection Practice (LexisNexis). To view a 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 5th edition of the *Assessment of Mental Capacity: A Practical Guide for Doctors and Lawyers* (BMA/Law Society 2019). To view full CV click [here](#).



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](#).



Nyasha Weinberg: Nyasha.Weinberg@39essex.com

Nyasha has a practice across public and private law, has appeared in the Court of Protection and has a particular interest in health and human rights issues. To view a 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](#).



Scotland editors

Adrian Ward: adrian@adward.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; honorary membership of the Law Society of 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

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

Alex is leading a masterclass on approaching complex capacity assessment with Dr Gareth Owen in London on 1 November 2023 as part of the Maudsley Learning programme of events. For more details, and to book (with an early bird price available until 31 July 2023), see [here](#).

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](#).

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.

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

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

Chambers UK Bar
Court of Protection:
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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

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