



Welcome to the September 2018 Mental Capacity Report. Highlights this month include:

- (1) In the Health, Welfare and Deprivation of Liberty Report: life-sustaining treatment and the courts, fertility treatment in extremis and an update on the Mental Capacity (Amendment) Bill;
- (2) In the Property and Affairs Report: inheritance tax planning and the MCA;
- (3) In the Practice and Procedure Report: a new Vice-President, a case study in poor care planning and its costs consequences, deprivation of liberty of children – the Court of Protection or Family Division?;
- (4) In the Wider Context Report: an important decision on disability and challenging behavior, guidance from the LGA, ADASS and RCN, and deprivation of liberty looked at overseas;
- (5) In the Scotland Report: disability discrimination and unfavourable treatment, AWI consultation response analysis published, and judicial training as part of increasing access to justice for people with disabilities;

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

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

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Life-sustaining treatment: the Supreme Court pronounces

An NHS Trust v Y & Ors [2018] UKSC 46 (Supreme Court (Lady Hale, President; Mance, Wilson, Hodge and Black SCJJ))

Best interests – medical treatment – practice and procedure (Court of Protection) – other

Summary

Background

Ever since the decision of the House of Lords in *Bland*, it has been recognised that CANH constitutes a medical treatment and that (as with any other medical treatment) it can be withdrawn where it is no longer in a patient's best interests without the medical practitioners being guilty of the offence of murder. Indeed, in *Aintree*, the Supreme Court made clear that the continued provision of CANH (or any other medical treatment) which was not in the patient's best interests would be actively unlawful.

The House of Lords in *Bland* suggested that it would be good practice for applications to be made to (then) the High Court for endorsement of the decision to withdraw CANH from those patients in a permanent vegetative state, at least until a body of experience and practice had built up which would obviate the need for such an

application. That would be so even where there was agreement between the families and the treating clinical team that continuing CANH was not in the person's best interests. Through a process of accretion described in the judgment of Lady Black in *Y*, the suggestion became crystallised into what was understood by many (in particular clinical practitioners) to be a legal requirement, and extended to include similar decisions in relation to those in a minimally conscious state. And so this position would have remained, causing, in many cases, considerable distress to families at the delay caused by the need to go to court in order to get endorsement of an agreed decision, had it not been for a series of awkward questions asked in 2017 as to the precise basis upon which the Code of Practice and Practice Direction 9E appeared to mandate that such decisions went to court.

Those awkward questions were ultimately posed in stark form in *Y's* case, where the NHS Trust responsible for the care of man in an MCS, whom both the family and treating team agreed should no longer receive CANH, went to the High Court to get a declaration that it did not need to approach the Court of Protection for endorsement of this position. The Trust went to the High Court rather than the Court of Protection, so that there could be no suggestion that it was accepting the jurisdiction of the Court

of Protection to make the decision (as had happened in *Re M*, leading to somewhat sterile arguments as to whether the resulting decision that the Trust need not have come to court was, or was not, obiter).

O'Farrell J held at first instance that the Trust did not, as a matter of law, have to seek the endorsement of the Court of Protection where the decision to withdraw CANH was an agreed one. The Official Solicitor, acting as Y's litigation friend, sought and obtained leave to 'leapfrog' the decision to the Supreme Court, albeit, by the time that the case reached the Supreme Court Mr Y had died after contracting acute respiratory sepsis. The Supreme Court nonetheless determined the appeal should go ahead because of the general importance of the issues raised.

The arguments

The Official Solicitor submitted that, in every case, court approval had to be sought before CANH could be withdrawn from a person with PDOC, thus ensuring that the patient's vulnerable position was properly safeguarded by representation through the Official Solicitor, who could obtain independent expert medical reports about his condition and prognosis, and make submissions to the court on his behalf if appropriate. The Official Solicitor derived this requirement essentially from the common law and/or the European Convention on Human Rights (ECHR), in particular Article 2 and Article 6. He also submitted that his position found support in the statutory Code of Practice to the MCA 2005, and it was irrelevant that neither the MCA 2005 nor the Court of Protection Rules specifically impose the requirement for which he contended. The intervenor Care Not Killing

supported the Official Solicitor, drawing particular attention to difficulties in diagnosis.

The Trust and CCG (the latter as the body funding Y's cases, and jointly represented with the Trust) argued, in response, that (1) Bland established no more than a rule of practice, (2) it was time for that blanket rule of practice to be dispensed with, and replaced by adherence to the detailed available professional guidance, and (3) there was no breach of human rights involved in withdrawal of CANH from a patient in a PDOC if continuation was not in their best interests. The British Medical Association, the Intensive Care Society and the Faculty of Intensive Medicine, intervening, supported the Trust/CCG's arguments, and also put before the court relevant professional guidance, material setting out the realities of decision-making in different clinical situations, highlighting the difficulty of carving out CANH withdrawal in PDOC from other forms of decisions routinely taken by doctors in conjunction with families.

The decision

In a detailed tour d'horizon, taking in the common law, the MCA 2005, the jurisprudence of the Court of Protection, the ECHR and relevant medical guidance, Lady Black, delivering judgment on behalf of the Supreme Court, concluded in clear terms that there was no requirement either at common law or under the ECHR for court approval to be sought in the way contended for by the Official Solicitor. Importantly, Lady Black also then took a step back from her "*intense focus upon the law*" to consider the issue in its wider setting. At paragraphs 116 ff, she held as follows:

116. It is important to acknowledge that CANH is more readily perceived as basic care than, say, artificial ventilation or the administration of antibiotics, and withholding or withdrawing it can therefore cause some people a greater unease. However, it was decided as far back as the Bland case that CANH is in fact to be seen as medical treatment. It is not easy to explain, therefore, why it should be treated differently from other forms of life-sustaining treatment, and yet that is the consequence of the legal position for which the Official Solicitor contends.

117. Furthermore, the Official Solicitor's focus is on only one sub-set of patients who are, for one reason or another, unable to take their own decisions about their medical care and in respect of whom life-sustaining treatment is under consideration. This is a point that Peter Jackson J made in *In re M (Incapacitated Person: Withdrawal of Treatment)*, and it emerges with some force from the written submissions of the BMA and of the ICS and the FICM. It is not only those, such as Mr Y, who suffer an acute episode and are then stabilised, who may require CANH. The need for it can arise also, for example, in the advanced stages of a degenerative neurological condition such as Huntington's disease or multiple sclerosis, or in the advanced stages of dementia, where there may be a recognised downward trajectory. Presently, the BMA say, in the case of patients who have suffered a severe stroke, or are significantly cognitively impaired but conscious, or are suffering from a degenerative neurological condition or other condition with a recognised downward trajectory, decisions to withhold or withdraw CANH are made on a regular basis without

recourse to the courts. The BMA can see no principled or logical reason for requiring court review in relation to patients with PVS and MCS but not for a patient with a different condition. Similarly, it can find no logical reason why one form of medical treatment, CANH, is treated differently from other forms of medical treatment such as artificial ventilation.

118. The submissions of the ICS and FICM are illuminating as to what occurs in units delivering critical care to patients. Most admissions to such units occur as an emergency, without the patient having made any advance decision about treatment, and possibly already so unwell that he or she has impaired consciousness or is unable to communicate wishes. Most decisions relating to medical treatment in the critical care setting, including as to whether life-sustaining treatment is withheld or withdrawn, have to be made without the participation of the patient. They are, we are told, "almost invariably taken on the basis of (in England & Wales) best interests and (in Scotland) benefit, on the basis of consensual decision-making as between the clinical team and the patient's family and carers". In that critical care setting, CANH is not considered differently from any other form of life-sustaining treatment. This is said to reflect "the reality in critically ill patients that it is the withdrawal of invasive or non-invasive ventilation, vasoactive medical and renal replacement therapy, and the 'double effect' from administration of medications to ensure patient comfort towards the end of life, that leads to the natural death of the patient, rather than cessation of CANH." It is likely, where CANH is withdrawn from a patient who is

clinically stable but suffering from a prolonged disorder of consciousness, that death will result from the withdrawal of CANH, so to this extent there is a difference between the two groups of patients. However, once CANH is seen as medical treatment, there is a parallel between the cases.

In an important passage finally dispelling what has become something of a myth that the diagnosis is all in determinations as to whether life-sustaining treatment should be continued, Lady Black made it clear that:

119. 119. In any event, I have difficulty in accepting that there are readily apparent and watertight categories of patient, with PDOC patients clearly differentiated from, say, patients with a degenerative neurological condition or critically ill patients, in such a way as to justify judicial involvement being required for the PDOC patients but not for the others. The dilemmas facing the medical team and those close to the patient may well be very similar in each of these cases. It would be a mistake to think, for example, that the intensive care doctor simply does whatever is necessary to stop the patient dying, no matter what the cost to the patient, any more than does the doctor looking after a PDOC patient or the stroke patient or the patient with Huntington's disease. In all of these cases, the medical team take their decisions as to treatment, whether it is CANH, or some other form of treatment such as artificial ventilation or cardio-pulmonary resuscitation or the administration of antibiotics, by determining what is in the patient's best interests. In so doing, the doctors will often have difficult diagnoses to make, reaching a prognosis may be challenging,

and the evaluation of the patient's best interests may not be entirely straightforward. All these tasks may call for considerable professional skill and individual judgement.

Lady Black made clear that she was sceptical as to whether it would, in fact, be possible to obtain a speedy court judgment in every case, as the Official Solicitor submitted should be the case, and, moreover, that:

121. As King LJ observed in In re Briggs, quite apart from the pressure that court cases place on the overstretched resources of NHS trusts, they add greatly to the strain on families facing acutely distressing decisions. In a case where all the proper procedures have been observed and there is no doubt about what is in the best interests of the patient, there is much to be said for enabling the family and the patient to spend their last days together without the burden and distraction, and possibly expense, of court proceedings. In addition, I do not disagree with Peter Jackson J's observation that there is a risk that the need to go to court might deflect clinicians and families from making true best interests decisions and might lead in some cases to inappropriate treatment continuing by default. Equally, it is not inconceivable that it might, as the BMA suggest, generate a reluctance, in some cases, to start CANH because of the procedures attending its withdrawal.

Although Lady Black accepted that diagnosis was not straightforward, and that developments in medical science "inevitably create new challenges of diagnosis and management, new uncertainties, for the medical profession," she noted that the survival of patients such as

Anthony Bland, then so unprecedented, “is now a well-established feature of medical practice.” Importantly, Lady Black then went on to outline how decision-making should happen:

124. [...] The documentation supplied to us¹ shows that the difficulty that there is in assessing the patient and in evaluating his or her best interests is well recognised. The process is the subject of proper professional guidance, covering vitally important matters such as the involvement in the decision-making process of a doctor with specialist knowledge of prolonged disorders of consciousness, and the obtaining of a second opinion from a senior independent clinician with no prior involvement in the patient’s care. The second opinion, as contemplated in the guidance (see paras 79 and 80 above, for example), is, in my view, a crucial part of the scrutiny that is essential for decisions of this sort, and the guidance sets parameters which should ensure that it is an effective check, in that the clinician who provides the second opinion must (so far as reasonably practical in the circumstances of the case) be external to the organisation caring for the patient, and is expected to carry out his or her own examination of the patient, consider and evaluate the medical records, review information about the patient’s best interests, and make his or her own judgement as to whether the decision to withdraw (or not to start) CANH is in the best interests of the patient. Thus the interests of patients and their families are safeguarded, as far as possible, against errors in diagnosis and evaluation,

premature decisions, and local variations in practice.

125. If, at the end of the medical process, it is apparent that the way forward is finely balanced, or there is a difference of medical opinion, or a lack of agreement to a proposed course of action from those with an interest in the patient’s welfare, a court application can and should be made. As the decisions of the ECtHR underline, this possibility of approaching a court in the event of doubts as to the best interests of the patient is an essential part of the protection of human rights. The assessments, evaluations and opinions assembled as part of the medical process will then form the core of the material available to the judge, together with such further expert and other evidence as may need to be placed before the court at that stage.

Lady Black therefore concluded that:

126 [...] having looked at the issue in its wider context as well as from a narrower legal perspective, I do not consider that it has been established that the common law or the ECHR, in combination or separately, give rise to the mandatory requirement, for which the Official Solicitor contends, to involve the court to decide upon the best interests of every patient with a prolonged disorder of consciousness before CANH can be withdrawn. If the provisions of the MCA 2005 are followed and the relevant guidance observed, and if there is agreement upon what is in the best interests of the patient, the patient may be treated in accordance with that

¹ Including separate guidance from the GMC, Royal College of Physicians, BMA and joint interim guidance from all three.

agreement without application to the court. I would therefore dismiss the appeal. In so doing, however, I would emphasise that, although application to court is not necessary in every case, there will undoubtedly be cases in which an application will be required (or desirable) because of the particular circumstances that appertain, and there should be no reticence about involving the court in such cases.

Comment

Practical implications

Following this decision, the position in England and Wales is now entirely clear. Where the provisions of the MCA 2005 are followed and the relevant guidance observed, and if there is agreement upon what is in the best interests of the patient, life-sustaining treatment (whether CANH or another form of such treatment) can be withdrawn (or withheld) without needing to make an application to the court. Of course, as Lady Black observed, if at the end of the process of decision-making the way forward is finely balanced, or there is a difference of medical opinion, or a lack of agreement to a proposed course of action from those with an interest in the patient's welfare, a court application can and should be made – so that the court can be asked to make this crucial decision on behalf of the patient. One immediate practical implication is that the joint guidance being worked on by the BMA, GMC and RCP can proceed to publication on the same basis that the interim guidance had been predicated; that guidance will set out a detailed decision-making process along the lines identified by Lady Black in her judgment.

Whilst the Supreme Court did not engage – as some had hoped it might – with the slightly Delphic observation of Lady Hale in *N v ACCG* that the general authority in s.5 will usually suffice to act in relation to the care and treatment of a person lacking capacity “*unless the decision is so serious that the court itself has said it must be taken to court,*” the same logic as set out by Lady Black in relation to life-sustaining treatment would, on its face, apply equally to other decisions that might fall to be made under the umbrella of s.5 (for instance, moving a person from their own home), with the added condition that, in many such cases, the person themselves may well be able to express wishes and feelings which should feature heavily in the mix in terms of identifying whether a court application is mandated.

Wider observations

One might ask whether the House of Lords in *Bland* that their (understandable) desire for caution merited the delay that ensued – and the return to the Supreme Court – before, in essence, it could be confirmed that a sufficient body of experience had been built up, and codified in clinical guidance, and the court could hand decision-making back to clinicians to undertake in conjunction with families. Be that it as it may, this judgment now makes the position absolutely clear.

Whilst the judgment is undoubtedly welcome at many levels, the handing back of this responsibility does carry with it the real need to ensure that the MCA is understood and applied with care and with attention to its spirit, as well as its letter, in the clinical context. The BMA/GMC/RCP guidance outlined above will undoubtedly help in the specific context of CANH

withdrawal. One might also think that the decision of the Supreme Court only makes it more important that careful consideration is given by Parliament during the passage of the Mental Capacity (Amendment) Bill as to whether s.5 needs to be given the additional 'teeth' in relation to decisions relating to serious medical treatment that had been proposed by the Law Commission but which the Government, at least at present, does not consider to be necessary.

Constructing consent to fertility treatment

Y v A Healthcare NHS Trust, the Human and Fertilisation and Embryology Authority and Z [2018] EWCOP 18 (Knowles J)

Best interests – practice and procedure (Court of Protection) – other

Summary

This was an application brought by Y, the wife of a dying man, Z for declarations that:

- notwithstanding Z's incapacity and his inability to consent, it was lawful and in his best interests for his sperm to be retrieved and stored prior to his death;
- An order pursuant to s.16 Mental Capacity Act 2005 directing that a suitable person should sign the relevant consent form for the storage of Z's sperm on his behalf.

Y and Z had been married for four years and had one child. They wanted a second child, but had been unable to conceive. They were referred to a fertility clinic by their GP for an appointment, prior to which Z provided a sperm sample for sperm analysis. Also prior to the appointment the couple filled out a number of forms directed to identifying the type of fertility treatment the

couple wanted. The court made finding that while filling out those forms the couple discussed the storage of Z's sperm, during which discussion Z had stated that if he died in the course of the fertility treatment he was supportive of Y proceeding with the fertility treatment if that is what she wanted to do.

The couple subsequently attended the fertility clinic appointment at which it was decided that they would proceed with IVF. A further appointment was made at which the treatment would begin.

Tragically prior to attending the second appointment, Z was involved in a road traffic accident in which he sustained a catastrophic brain injury. It was agreed that if on brain stem testing, Z had no brain activity, all treatment would be withdrawn and he would die. Y wanted to delay Z's death in order to retrieve his sperm to allow her to pursue the fertility treatment they had both agreed upon.

Given the findings of fact in relation to Z's recently expressed wishes about the IVF treatment, the question of whether it was in Z's best interests for the sperm to be obtained and stored was not a difficult one for the court. Mrs Justice Knowles held that it was.

More difficult was the question of the court giving the necessary consents for Z's sperm to be stored. Schedule 3 of the Human Fertilisation and Embryology Act 1990 ('HFEA 1990') governs the consents for the storage of sperm.

Sub-paragraph 1(1) of the Schedule states that:

A consent under this Schedule, and any notice under paragraph 4 varying or withdrawing a consent under this

Schedule, must be in writing and, subject to sub-paragraph (2), must be signed by the person giving it.

Sub-paragraph 1(2) of the schedule states that a consent by a person who is unable to sign because of illness, injury or physical disability may comply with the requirement of sub-paragraph 1(1) as to signature *"if it is signed at the direction of the person unable to sign, in the presence of the person unable to sign and in the presence of at least one witness who attests the signature."*

The court held that: *"the consent provisions are carefully drawn for sound public policy reasons, namely that consent is central to effective regulation in this area. They are couched in the imperative for that very reason."*

The court proceeded on the basis that it was doubtful that the forms that Z had signed were sufficient to comply with paragraph 1(1) of Schedule 3. What the court was therefore being asked to do was to authorise (pursuant to s.16 MCA 2005) a family member (not Y) to consent to the storage of Z's sperm on his behalf pursuant to paragraph 1(2) of Schedule 3. The court gave that consent, noting that, to comply with the provisions of the schedule, the family member would need to execute the consents in Z's presence before he died or was declared to be dead and in the presence of a witness.

The court also, on its own volition, gave consent for Z's sperm to be used for the fertility treatment.

Comment

One could not conceive of a case in which the merits of the application being granted were any

stronger. However, we observe that there are two issues which on their face would appear to have stood as a bar to the order being made. Neither were addressed in the judgment, although it may well have been that they were canvassed before the court:

1. The first is that it is difficult to understand from the judgment itself how the court came to the view that the s.16 MCA 2005 order would comply with the terms of paragraph 1(2) of Schedule 3 insofar as that paragraph requires the consent given on behalf of Z to be at his "direction." There is no doubt that the court was of the view that Z himself would have consented to the storage of the sperm had he been able to. Paragraph 1(2) however seems to demand more than simply identifying what the incapacitated person would have chosen to do. It requires the incapacitated person (here, Z) to direct that the third party gives the consent on his behalf. Given the circumstances of Z's loss of capacity (sudden and unpredicted) there would have been no opportunity for such direction.
2. The second – linked – problem is that s.27(2)(i) MCA 2005 specifically prohibits anyone, including the court, from *"giving a consent under the Human Fertilisation and Embryology Act 2008."* It may have been that the court considered that it was not, in fact, consenting on Z's behalf within the terms of the HFEA 1990, but directing (on Z's behalf) a relative to execute that consent. That undoubtedly represents a purposive (some might say strained) reading of the wording 'consent' in s.27(2)(i) MCA 2005, which on its face and in its context is addressed to the

material giving of consent (i.e. the fact of consenting to storage) rather than the technical execution of the written consent document.

Mental Capacity (Amendment) Bill update

The first day of the Lords Committee stage of the Mental Capacity (Amendment) Bill took place on 5 September. The Hansard transcript can be found [here](#) and [here](#) (including a name-check for the Special Report we published ahead of the debate). For those wanting to understand how, precisely, the government sees the Bill working, the key responses by Lord O'Shaughnessy (Parliamentary Under-Secretary of State, DHSC) to an extensive series of probing amendments put forward by peers can be found [here](#). All the amendments debated on 5 September were withdrawn (or associated amendments not moved), so no changes were made to the Bill at this stage. The next day of Committee stage will be 15 October; the easiest place to keep abreast of amendments is this page [here](#).

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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](#).

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Adrian is a recognised national and international expert in adult incapacity law. While still practising he acted in or instructed many leading cases in the field. 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.



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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, Alzheimer Scotland's Human Rights and Public Policy Committee, the South East Scotland Research Ethics Committee 1, and the Scottish Human Rights Commission Research Advisory Group. 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

Conferences at which editors/contributors are speaking

Switalskis Annual Review of the Mental Capacity Act

Neil is speaking at the 10th Annual Review of the MCA in York on 18 October 2018. For more details, and to book, see [here](#).

Taking Stock

Neil and Alex are speaking at the annual Approved Mental Health Professionals Association/University of Manchester taking stock conference on 16 November. For more details, and to book, see [here](#).

Other events of interest

Peter Edwards Law has announced its autumn programme of training in mental capacity and mental health, full details of which can be found [here](#).

Advertising conferences and training events

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

Our next edition will be out in early October. 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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