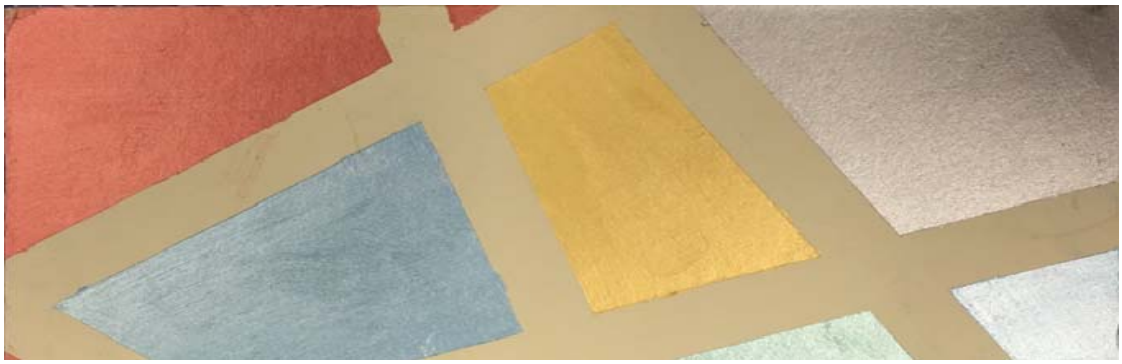
Essex CHAMBERS

MENTAL CAPACITY REPORT:
THE WIDER CONTEXT
April 2018 | Issue 84



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

(1) In the Health, Welfare and Deprivation of Liberty Report: the Government responds to the Law Commission's *Mental Capacity and Deprivation of Liberty* report, the Joint Committee on Human Rights rolls up its sleeves, and exploring the outer limits of best interests;

(2) In the Property and Affairs Report: a guest article by Denzil Lush on statutory wills and substituted judgment and the *Dunhill v Burgin* saga concludes;

(2) In the Practice and Procedure Report: an unfortunate judicial wrong turn on 'foreign' powers of attorney, the new Equal Treatment Bench book, and robust case management gone too far;

(3) In the Wider Context Report: appointeeship under the spotlight again, a CRPD update and the Indian Supreme Court considers life-sustaining treatment;

(4) In the Scotland Report: the Mental Welfare Commission examines advocacy, a new Practice Note from the Edinburgh Sheriff Court and a Scottish perspective on the judicial wrong turn on 'foreign' powers;

You can find all our past issues, our case summaries, and more on our dedicated sub-site here, and our one-pagers of key cases on the SCIE website.

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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.

Contents

ENGLAND AND WALES

Ordinary residence and incapacity

The Department of Health and Social Care has published anonymised determinations from 2017 in ordinary residence disputes between health and social care authorities.

All ten determinations are by their nature very fact-specific, but can provide useful examples for practitioners generally seeking to apply the labyrinth rules on ordinary residence. The classic test in *Shah v London Borough of Barnet* [1983] 1 All ER 226 of voluntary adoption of a place of residence does not apply directly to those who lack capacity to decide where to reside. In *R (Cornwall Council) v Secretary of State for the Home Department* [2015] UKSC 46, the Supreme Court held that the question was whether the relevant person's period of actual residence was sufficiently "settled" to amount to ordinary residence.

Readers may be particularly interested in OR6, OR5, OR3, OR2 and OR1 in the 2017 determinations, concerning individuals who lacked capacity to make decisions about their residence and care:

- OR6 – Between 1997 and 2006, P lived with her mother in Council A. Between 2006 and 2009, P attended school in Council C and was later provided with accommodation in

Council C. She returned to Council A briefly for a month in late 2009, pending a placement in Council B. She was placed in Council B from 2010 until she moved to a new placement in Council D as a result of Court of Protection proceedings in 2017. The Secretary of State determined that P was, and had been, ordinarily resident in Council B from around 1 January 2010 and deemed to continue to be ordinarily resident there.

- OR5 – Until July 2014, P lived at home with her husband in the area of Council A. On 7 July 2014, P went to stay at a care home located in Council B's area arranged by P's husband. P's husband intended this to be a temporary move. P appeared to settle very well and wished to remain at the care home in Council B. The Secretary of State determined that P was ordinarily resident in Council A at the relevant date in July 2014.
- OR3 – Until May 2012, P lived with his parents in the area of Council A before moving to supported living. He was detained under the Mental Health Act 1983 in March 2013 and discharged in November 2013 to live with his family. In February 2014, the Court of Protection decided that it was in P's best interests to reside at a supported living placement in Council B. P moved to Council B on 10 February 2014. The Secretary of State determined that P became ordinarily residence in Council B on 10 February 2014.
- OR2 – P had been living in the area of Council B since at least 20 April 2011. Council A were involved in arranging P's placement (described as a supported living placement) and they were responsible for his community care. However, Council A did not have responsibility for meeting P's accommodation costs. The Secretary of State determined that P was ordinarily resident in the area of Council B from 20 April 2011.
- OR1 – In October 2011, P moved to a supported living placement in the area of Council B. Prior to that, she resided in the area of Council A where she had friends and family. On 30 January 2015, a best interests' decision was taken that it was in P's best interests to remain at the placement in Council B. The Secretary of State determined that P was, and had been, ordinarily resident in Council B since October 2011.

In related news, we have updated our (free) Guidance Note on Mental Capacity and Ordinary Residence.

Appointeeship (again) – and proceedings before the FTT

RH v Secretary of State for Work and Pensions (DLA) [2018] UKUT 48 (AAC) (Upper Tribunal (AAC) (UTJ Rowland))

Other proceedings

Summary

This case concerned an appeal by the claimant's father against a decision of the First-tier Tribunal as to the claimant's entitlement to disability living allowance (DLA) during a period of time when the claimant was in hospital and then in a residential care home. The decision is of interest for its discussion about the claimant's capacity to conduct the appeal and the consequent need

for a litigation friend to be appointed in the proceedings before the application for permission to appeal could be determined.

The claimant had suffered from mental illness for a long time. In 1999, the claimant's mother applied to the Secretary of State to be appointed as the claimant's appointee to manage his benefits. In late 2009, the local authority Medway Borough Council applied to become the appointee. The Secretary of State wrote to the claimant's mother asking whether she would relinquish her role as appointee but RH's mother refused. Nonetheless, the Secretary of State went on to appoint Medway Council as the claimant's appointee and ceased making payments to RH's mother but made them to Medway Council instead.

There was some discussion in the judgment as to whether Medway Council had been validly appointed given the objections of the claimant's mother and the failure of the Secretary of State to formally notify the claimant's mother that her appointment had been revoked. However, the judge ultimately concluded that it was obvious from the circumstances that the claimant's mother must have been aware that she was no longer being treated as the appointee and that Medway Council had in fact been appointed.

What was more unclear was whether the claimant had the mental capacity to conduct these proceedings and the need to resolve that issue in order to determine the application. The local authority was not aware of any capacity assessment of the claimant and offered exceptionally to pay for an assessment and for an independent mental capacity advocate to put RH's arguments to the Upper Tribunal. The local authority argued that the appeal raised important issues other than those relating to the narrow issue of the claimant's entitlement to disability living allowance which justified transferring the case to the High Court, and that, if RH lacked capacity, it would unfair that those issues should be decided without a litigation friend being appointed to make representations on the claimant's behalf. The Secretary of State opposed the local authority's request to transfer the case to the High Court and argued that the application for permission to appeal had no merit and should be dismissed.

The judge readily acknowledged that the First-tier Tribunal had the power to appoint a litigation friend (citing *AM (Afghanistan) v Secretary of State for the Home Department* [2017] EWCA Civ 1123 reported in our September 2017 report. However, whilst it remained unclear whether the claimant had capacity to conduct proceedings, the judge held that it was not necessary to resolve that issue because, even assuming the claimant lacked capacity to conduct litigation, there was no real risk of unfairness to him. As the judge explained at paragraph 39:

> *…for as long as there is an appointee, any benefit awarded as a result of the appeal will be paid to the appointee and so the claimant is protected in that way in any event. All these considerations mean that, in most cases where there is an appointee, it would simply be disproportionate to obtain the evidence necessary to make an assessment of capacity so as to be able to decide whether a person who has apparently been appointed as a litigation friend."*

The appeal had been brought by the claimant's father on the claimant's behalf and both the Secretary of State and Medway Council agreed

that, if the claimant lacked capacity and his father consented to the appointment, it would have been appropriate to appoint him as the claimant's litigation friend. Thus, the judge *"would have accepted that the claimant's interests were being adequately advanced and protected by the claimant's father and the appointee between them."*

The judge gave the following general guidance at paragraphs 44-45:

> *44. In considering whether there is unfairness in proceeding without a litigation friend, the starting point must be that, as I have said above, it is generally to be presumed that a claimant who lacks capacity is adequately represented by an appointee and does not need a litigation friend unless the claimant, or a person wishing to act on the claimant's behalf, comes forward and wishes to advance an argument that the appointee is not advancing. Therefore, if a person has been acting on the claimant's behalf but no longer wishes to do so, it may be appropriate to fall back on the presumption and consider the claimant's interests adequately to be protected by the appointee together with the investigatory approach of the expert tribunal, which may enable it to determine an issue identified on behalf of the claimant without it being necessary for the claimant or a litigation friend to take any further action. However, this will depend on the circumstances. In particular, it will be relevant whether the tribunal considers that the appointee is failing to take points that ought to be taken on behalf of the claimant or that there ought to be an opportunity for further evidence to be advanced on behalf of the claimant.*
>
> *45. It is also highly relevant what decisions the tribunal is minded to make. I find it difficult to imagine lack of a litigation friend making it unfair to decide a point entirely in favour of the claimant, even though deciding the same point against the claimant without a litigation friend having been appointed might be unfair. Nor, at least in this case, can I see any unfairness in me deciding, without a litigation friend having been appointed, issues that are neutral in their effect on the substantive application for permission to appeal, including deciding that certain issues do not need to be decided. As to the substantive application itself, it is for permission to appeal on a point of law in an area of the law in which the Upper Tribunal has considerable experience and frequently raises issues of law that have not been advanced by the parties. The grounds of appeal and other documents identify the arguments that the claimant's father wished to advance. Evidence is not required. The claimant's father is no longer prepared to act on behalf of the claimant. The appointee has instructed counsel and I do not consider that there is any point that could be taken in the claimant's interests that has not been taken. In all these circumstances, I am satisfied that, even if the claimant lacks capacity, I can fairly determine this application and the issues arising in relation to it without it being necessary to appoint a litigation friend to act on behalf of the claimant."*

Counsel for Medway also sought to argue that the procedures, or lack of them, in relation to appointees, their appointment, revocation etc were incompatible with the ECHR and Article 12.4 of the United Nations Convention on the

Rights of Person with Disabilities which provides that:

> *4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.*

To advance those arguments, he argued, unsuccessfully, that the case should be transferred to the High Court.

In the end, the Tribunal decided the issues without a transfer and without reference to the ECHR or the UN Convention, holding that the revocation and appointment of Medway was, despite its informality and lack of notice, valid, see paragraph 28 of the judgment.

Comment

There is a strong sense of pragmatism in Judge Rowland's reasoning as regards the approach that the Tribunal should take to capacity and representation.

As with the *DB* case we reported upon in our March Report, this case again illustrates the unsatisfactory nature of the appointeeship regime. It is entirely in the hands of the Secretary of State, there are no procedures to be followed and no controls over appointees. If and when the ECHR and CRPD arguments advanced in the *Medway* case are given a proper outing we suspect that whole edifice really will start to crumble.

Care home staff – their own views of care

In the largest-ever survey of care home staff, carried out by researchers at UCL and reported in the journal *PLOS ONE*: 51% reported carrying out or observing one or more potentially abusive or neglectful behaviour at least sometimes in the preceding 3 months, and some abuse was reported as happening "at least sometimes" in 91/92 care homes. Examples of positive behavior were also given, but the overall tenor of the study is not reassuring.

Learning disability care and NICE

In its new guideline *Learning disabilities and behaviour that challenges: service design and delivery*, NICE emphasises that care for those with learning disabilities should be provided close to home wherever possible.

The guideline says local authorities and CCGs should take joint responsibility and put one person, who has experience of working with people with learning disabilities and behaviour that challenges, in charge of designing services

This lead commissioner should work together with people using services and their families to develop a clear plan to support people with learning disabilities and challenging behaviour. They should base the plan on good local evidence such as local registers. Budgets and resources should be pooled across health, social

care and education. This could be done across neighbouring authorities for the most specialist support services.

The guideline also emphasises the need to plan ahead to reduce the chances of a crisis arising and calls for resources to be in place to respond quickly, for example by providing an out-of-hours helpline.

NICE says adults with learning disabilities who have behaviour that challenges should be offered the option of living on their own if they prefer this and can get appropriate support to do so. As an alternative they can be offered shared housing with a small number of people.

The guideline says each person should have a singled named worker, like a social worker or community nurse, who can have regular meetings with them to discuss their needs.

The guideline emphasises the need to provide families with support as early as possible. This includes providing practical advice on how to care for their loved one, access to short breaks away from their caring duties and details of available local services.

NICE says people with a learning disability and behaviour that challenges should not be admitted to inpatient mental health units unless all other possible options have been considered and exhausted.

Open University course on mental capacity

A free online course on understanding mental capacity (across the UK) is available from the Open University here, which may well be of assistance to those who need to get an overview both of the concepts of mental capacity and the relevant legal frameworks.

Prader-Willi Syndrome and mental capacity

The Prader-Willi Society has published guidance on the application of the MCA 2005 in the specific, and often complex, context of Prader-Willi Syndrome.

Domestic abuse consultation: a chance to think more widely

The Government launched on 8 March a consultation on the approach to take to domestic abuse, which closes on 31 May. The proposed – statutory - definition of domestic abuse, opening the way both to criminal sanctions and a new 'domestic abuse protection order,' is

> *Any incident or pattern of incidents of controlling, coercive, threatening behaviour, violence or abuse between those aged 16 or over who are, or have been, intimate partners or family members regardless of gender or sexual orientation. The abuse can encompass, but is not limited to:*
> *• psychological*
> *• physical*
> *• sexual*
> *• economic*
> *• emotional*

The consultation represents a hugely important potential step forward in the domestic abuse context. Readers may also think that – given the near-impossibility of finding legislative time at present – it may also provide the only opportunity that may present itself for some considerable time to consider whether the definition should also include what might be

termed 'proximity abuse.' This would capture those who appear to have mental capacity in the relevant domains but are:

1. Being controlled, coerced or abused by those in close physical proximity but where there is no family/intimate relationship: see, for instance, the multiple judgments in the *G* cases for an example where having straightforward relief would have been of very considerable assistance in terms of ensuring that there was a clear route to follow;

2. 'Groomed' or otherwise exploited by those who portray themselves as a friend or intimate of the individual, but are no such thing. The gaps in the law in this area were vividly highlighted by the report of David Spicer into the sexual exploitation of young women in Newcastle.

As readers know, this is an area which has troubled Alex greatly for some time; his attempts to persuade the Law Commission to undertake a project in the area ultimately foundered on a lack of Government commitment to take it forward. This may, though, provide an opportunity to return to the fray, and he would welcome any observations/assistance that readers would care to provide. In this context, they may also be interested to note that the Government of Singapore is moving ahead with legislation in the form of a Vulnerable Adults Bill.

Forced marriage resources launched by the University of Nottingham

'My Marriage My Choice' is a two year study, funded by the National Institute for Health Research - School of Social Care Research (NIHR-SSCR). The study is exploring forced marriage of adults with learning disabilities from a safeguarding perspective. The aim of the project is to increase professionals' recognition of forced marriages, reduce forced marriage and develop resources to support effective adult safeguarding practice in the area.

The objectives of the project are identified as being:

- to identify the individual and cultural characteristics of people with a learning disability who are at risk of or have been subjected to forced marriage;

- to generate knowledge about how key stakeholders, including people with learning disabilities, their families, community/faith leaders and professionals, understand issues of consent, capacity and forced marriage;

- to develop resources for use by lay and professional stakeholders to raise awareness of the forced marriage of people with learning disabilities and support more effective safeguarding interventions when necessary. Outputs will be produced which:

- explain forced marriage from the perspective of people with learning disabilities, family members and community/faith leaders through the use of detailed case studies thus improving understanding of social care staff

- raise awareness of family members and community/faith leaders about the consequences of forced marriage

- provide a framework for adult social care staff to support recognition of forced

marriage and managing the complexities involved, including a tool for assessing capacity to consent to marriage

- provide advice to adults with learning disabilities on recognising forced marriage and where to get help (in accessible format).
- To disseminate the findings, including practice-related outputs, to service users, frontline practitioners, managers and policy-makers, and academic audiences

It is being led by Rachael Clawson, Assistant Professor in Social Work at The University of Nottingham (who wrote the multi-agency practice guidelines *Forced Marriage and Learning Disabilities* published by the Home Office/Foreign and Commonwealth Office Forced Marriage Unit in 2010), in collaboration with colleagues at University of Kent, at RESPOND and the Ann Craft Trust.

Permission was given to undertake the first ever analysis of data held by the Forced Marriage Unit (FMU) on cases involving people with learning disabilities. Further data was gathered from people with learning disabilities; family members; community/faith leaders and practitioners to gain multiple perspectives on this complex issue. If you would like to get in touch with the project, they can be contacted at mymarriagemychoice@nottingham.ac.uk, and resources produced by the project should be available shortly at the project website.

Mental Health Tribunal rule change consultation

The Tribunal Procedure Committee has launched a consultation on whether the MHT rules (in England) should be amended to (1) remove pre-hearing medical examinations; and (2) increase the number of circumstances under which paper hearings take place has opened. The consultation runs until 14 June.

The MHA in practice

Two recent reports shed important, and in some cases disturbing, light upon how the MHA is being implemented in practice, and the pressures that are upon the professionals operating within that system.

The Parliamentary and Health Service Ombudsman reported on 20 March on an analysis of over 200 mental health complaints upheld by the Ombudsman, identifying 5 key themes:

- Failure to diagnose and/or treat the patient;
- Inappropriate hospital discharge and aftercare of the patient;
- Poor risk assessment and safety practices;
- Not treating patients with dignity and/or infringing human rights;
- Poor communication with the patient and/or their family or carers.

The CQC has published the result of a collaborative review carried out in 2017 with national partners and local Approved Mental Health Professionals (AMHPs) to identify themes that support or challenge the effective running of AMHP services. Alongside factors supporting the effective delivery of AMHP services, the CQC identified the following challenges and barriers to the AMHP role

- Acute care system capacity: AMHPs reported that a national reduction in beds

affected their ability to complete assessments in a timely manner.

- Workforce: AMHPs talked about an inability to recruit and retain AMHPs.
- Variation in health and social care integration: Integration of services varied across areas and services.
- Mental health commissioning: AMHPs recognised the importance of good, integrated, local commissioning arrangements to their role.

INTERNATIONAL NEWS

How well do you know your loved ones?

An interesting paper[1] published in the British Medical Journal by Canadian researchers sought to analyse whether an advance directive was more or less effective than a proxy decision-maker (such as an attorney) in correctly reflecting the healthcare preferences of elderly people.

Competent adults aged 70 and over were invited to record their healthcare preferences. Around 3 months later, they were interviewed and placed in hypothetical situations of incapacity where a medical decision needed to be made. They were asked whether they would want to receive four medical interventions (intravenous antibiotics, gallbladder surgery for cholecystitis, permanent tube feeding and cardiopulmonary resuscitation) assuming that they had severe dementia at the time the intervention was required. Their chosen proxy (mostly their spouse and for some their child) were asked to guess the other's answers in the various scenarios.

Unsurprisingly, the answers the people gave as to their own preferences three months after completing an advance directive were more likely to be similar to their original position (and thus thought to be accurate) than were the views given by their proxies, who had attended the initial workshop with them. The degree of agreement between the person and their proxy ranged from 43% to 83% across the scenarios so the accuracy of proxy judgments is often poor. This was despite half of the participants' having discussed their preferences with their proxy prior to enrolling in the study. The findings suggest that advance preferences might provide a better insight into a person's wishes than their proxy, although neither source is perfect.

The authors conclude that "[f]*indings suggest that a directive might provide better insight into a person's wishes than the person's proxy, although neither source is perfect. A multifaceted decision-making model that includes both sources of information might better serve the interests of older adults who have lost the capacity to make decisions on their own.*"

Treatment withdrawal – the Indian Supreme Court perspective

On 9 March 2018, a five judge bench of the Indian Supreme Court handed down judgement in *A Registered Society v Union India***.** The

[1] Bravo G, Sene M, Arcand M: Making medical decisions for an incompetent older adult when both a proxy and an advance directive are available: which is more likely to reflect the older adult's preferences? *Journal of Medical Ethics* Published Online First: 09 March 2018. doi: 10.1136/medethics-2017-104203

judgment runs to over 500 pages and is a determination of an application brought by a registered society for (inter alia):

- Declaratory relief that the right to die with dignity is a fundamental right within the fold of the right to live with dignity guaranteed under Article 21 of the Constitution.[2]
- To "*ensure that persons of deteriorated health or terminally ill patients should be able to execute a document titled —My Living Will and Attorney Authorisation - which can be presented to the hospital for appropriate action in the event of the executant being admitted to the hospital with serious illness which may threaten termination of the life of the executant*." (para 6)

The motivation behind the application was stated to be that with "*the advancement of modern medical technology pertaining to medical science and respiration, a situation has been created where the dying process of the patient is unnecessarily prolonged causing distress and agony to the patient as well as to the near and dear ones and, consequently, the patient is in a persistent vegetative state thereby allowing free intrusion*." (paragraph 8).

Four different judgments were delivered by a Bench comprising the Chief Justice of India Dipak Misra, Justice Khanwilkar (the first judgment), Justice A.K. Sikri (the second judgement), Justice Chandrachud (the third judgment) and Justice Ashok Bhushan (the fourth judgment).

Article 21 of the Indian Constitution

The leading judgment was delivered by Chief Justice Misra and Justice Khanwilkar. The Court concluded at para 160 that:

> *the right to life with dignity has to include the smoothening of the process of dying when the person is in a vegetative state or is living exclusively by the administration of artificial aid that prolongs the life by arresting the dignified and inevitable process of dying. Here, the issue of choice also comes in. Thus analysed, we are disposed to think that such a right would come within the ambit of Article 21 of the Constitution.*

This conclusion was adopted by all of the Judges, of note is the judgment of

- Justice Chandrachud who held that:

> *'Every individual has a constitutionally protected expectation that the dignity which attaches to life must subsist even in the culminating phase of human existence. Dignity of life must encompass dignity in the stages of living which lead up to the end of life. Dignity in the process of dying is as much a part of the right to life under Article 21. To deprive an individual of dignity towards the end of life is to deprive the individual of a meaningful existence. Hence, the Constitution protects the legitimate expectation of every person to lead a life of dignity until death occurs'*

- Justice Ashok Bhushan who noted that as someone who is competent can refuse or

[2] '*No person shall be deprived of his life or personal liberty except according to procedure established by law*'

withdraw life sustaining treatment, "*the right of a patient who is incompetent to express his view cannot be outside of fold of Article 21 of the Constitution of India*." He further held that "*in cases of incompetent patients who are unable to take an informed decision, 'the best interests principle'* [should] *be applied and such decision be taken by specified competent medical experts and be implemented after providing a cooling period to enable aggrieved person to approach the court of law*."

The second issue: Advance directives/Living wills

Again the leading judgment on this issue was delivered by Chief Justice Misra and Justice Khanwilkar's. The Court held at paragraph 188 that as there is no legal framework in India as regards the Advance Medical Directive the Court had a constitutional obligation to protect the right of the citizens as enshrined under Article 21 of the Constitution. The Court went on to conclude at para 191 that "*Advance Medical Directive would serve as a fruitful means to facilitate the fructification of the sacrosanct right to life with dignity*" but held that procedural safeguards were required. These were set out as follows:

- It must be executed by an adult of sound mind.
- It must be voluntarily executed.
- It should be the result of informed consent.
- It must be in writing clearly stating as to when medical treatment may be withdrawn or no specific medical treatment given which will only have the effect of delaying the process of death that may otherwise cause him/her pain, anguish and suffering and further put him/her in a state of indignity.

The Court went on to detail at some considerable length when and by whom such a document can be given effect to. This is a complex scheme with a number of safeguards, and is well worth reading in full (see paragraphs 191(d)). In summary:

(i) In the event the executor becomes terminally ill and is undergoing prolonged medical treatment with no hope of recovery and cure of the ailment, the treating physician, when made aware about the Advance Directive, must take specific steps to ascertain the genuineness and authenticity of the document before acting upon it.

(ii) The instructions in the document must be given due weight by the doctors. However, it should be given effect to only after being fully satisfied that the executor is terminally ill and is undergoing prolonged treatment or is surviving on life support and that the illness of the executor is incurable or there is no hope of him/her being cured.

(iii) If the physician treating the patient (executor of the document) is satisfied that the instructions given in the document need to be acted upon, he shall inform the executor or his guardian / close relative, as the case may be, about the nature of illness, the availability of medical care and consequences of alternative forms of treatment and the consequences of remaining untreated. He must also ensure that he believes on reasonable grounds that the person in question understands the

information provided, has cogitated over the options and has come to a firm view that the option of withdrawal or refusal of medical treatment is the best choice.

(iv) The physician/hospital where the executor has been admitted for medical treatment shall then constitute a Medical Board consisting of the Head of the treating Department and at least three experts from the fields of general medicine, cardiology, neurology, nephrology, psychiatry or oncology with experience in critical care and with overall standing in the medical profession of at least twenty years who, in turn, shall visit the patient in the presence of his guardian/close relative and form an opinion whether to certify or not to certify carrying out the instructions of withdrawal or refusal of further medical treatment. This decision shall be regarded as a preliminary opinion.

(v) Thereafter the 'Jurisdictional Collector' is informed and has to form a further Medical Board comprising the Chief District Medical Officer of the concerned district as the Chairman and three expert doctors from the fields of general medicine, cardiology, neurology, nephrology, psychiatry or oncology with experience in critical care. They shall jointly visit the hospital where the patient is admitted and if they concur with the initial decision of the Medical Board of the hospital, they may endorse the certificate to carry out the instructions given in the Advance Directive.

(vi) The Board constituted by the Collector must beforehand ascertain the wishes of the executor if he is in a position to communicate and is capable of understanding the consequences of withdrawal of medical treatment. In the event the executor is incapable of taking decision or develops impaired decision making capacity, then the consent of the guardian nominated by the executor in the Advance Directive should be obtained regarding refusal or withdrawal of medical treatment to the executor to the extent of and consistent with the clear instructions given in the Advance Directive.

(vii) The Chairman of the Medical Board nominated by the Collector, that is, the Chief District Medical Officer, shall convey the decision of the Board to the jurisdictional JMFC (the body involved in the actual execution of the document) before giving effect to the decision to withdraw the medical treatment administered to the executor. The JMFC shall visit the patient at the earliest and, after examining all aspects, authorise the implementation of the decision of the Board.

(viii) It will be open to the executor to revoke the document at any stage before it is acted upon and implemented.

In the event that permission to withdraw medical treatment is not granted by the Medical Board, an application to the Court can be made by the executor, the hospital or treating clinician, or family members. The High Court will be free to constitute an independent Committee consisting of three doctors from the fields of general medicine, cardiology, neurology, nephrology, psychiatry or oncology with experience in critical care.

The Judgment also sets out provisions for withdrawing the Advance Directive, and for practitioners to establish if it is inapplicable. In the event that a Hospital Medical Board takes a decision not to follow an Advance Directive while treating a person, then it shall make an application to the Medical Board constituted by the Collector for consideration and appropriate direction on the Advance Directive.

The judgment also addresses what should be done where a patient does not have an Advance Directive. The process set out is effectively the same, however the process is started not by the fact of the Advance Directive, but because the patient is terminally ill and undergoing prolonged treatment in respect of an ailment which is incurable or where there is no hope of being cured. In such circumstances the physician may inform the hospital which, in turn, shall constitute a Hospital Medical Board as set out above.

In the event the Hospital Medical Board certifies the option of withdrawal or refusal of further medical treatment, the hospital shall immediately inform the jurisdictional Collector and the same process as set out above is invoked.

The other judges all agreed with the scheme outlined by the Chief Justice, Justice Sikri adding what he described as a 'a pious hope' that the *'legislature would step in at the earliest and enact a comprehensive law on 'living will/advance directive' so that there is a proper statutory regime to govern various aspects and nuances thereof which also take care of the apprehensions that are expressed against euthanasia[3].'*

Comment

The depth and breadth of this judgment is immense. The judgments traverse an enormous wealth of philosophical, moral, religious and legal material from around the globe. We hope that we may be forgiven for being a little proud that in a judgment which quotes from the most influential thinkers in world history it also includes reference to an article on the 39 Essex Chambers website by a certain A Ruck Keene!

The judgment has been provided to the UK Supreme Court who are currently deciding on the procedural requirements on clinicians to bring cases for withdrawal of CANH in PVS and MCS patients before the case (*Re Y*).

CRPD updates

In an unusual step, the Committee on the Rights of Persons with Disabilities has published a correction to General Comment 1, on Article 12 and equal recognition before the law. The original version provided, at paragraph 27, that substitute decision-making regimes, which the Committee considers are impermissible by reference to the CRPD:

> *can take many different forms, including plenary guardianship, judicial interdiction and partial guardianship. However, these regimes have certain common characteristics: they can be defined as systems where (i) legal capacity is removed from a person, even if this is in respect of a single decision; (ii) a substitute decision-maker can be*

[3] In this context this means passive euthanasia i.e. the withholding of life-prolonging measures and resources, as opposed to active steps to bring about a person's death.

> *appointed by someone other than the person concerned, and this can be done against his or her will; and (iii) any decision made by a substitute decision-maker is based on what is believed to be in the objective "best interests" of the person concerned, as opposed to being based on the person's own will and preferences.*

The corrected version reads the same, save for the replacement of a key 'and' with an 'or':

> *can take many different forms, including plenary guardianship, judicial interdiction and partial guardianship. However, these regimes have certain common characteristics: they can be defined as systems where (i) legal capacity is removed from a person, even if this is in respect of a single decision; (ii) a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will; **OR** (iii) any decision made by a substitute decision-maker is based on what is believed to be in the objective "best interests" of the person concerned, as opposed to being based on the person's own will and preferences.*

It will be seen that this – disjunctive – definition captures a very much wider group of legal frameworks than the General Comment as published, as any one of the circumstances outlined in the paragraph is – on the Committee's interpretation of Article 12 – impermissible. It is undoubtedly the case that this reflects the underlying intention of the Committee, so this is clearly a correction, rather than a further expansion of their interpretation.

That the Committee's interpretation of Article 12 is not shared by all states[4] was confirmed when the Republic of Ireland ratified the CRPD, to take effect on 19 April 2018. Ireland entered the following declarations and reservations:

> *Declaration and reservation: Article 12*
> *Ireland recognises that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. Ireland declares its understanding that the Convention permits supported and substitute decision-making arrangements which provide for decisions to be made on behalf of a person, where such arrangements are necessary, in accordance with the law, and subject to appropriate and effective safeguards.*
>
> *To the extent article 12 may be interpreted as requiring the elimination of all substitute decision making arrangements, Ireland reserves the right to permit such arrangements in appropriate circumstances and subject to appropriate and effective safeguards.*
>
> *Declaration: Articles 12 and 14*
>
> *Ireland recognises that all persons with disabilities enjoy the right to liberty and security of person, and a right to respect for physical and mental integrity on an equal basis with others. Furthermore, Ireland declares its understanding that the Convention allows for compulsory care or treatment of persons, including measures to treat mental disorders,*

[4] See in this regard, for instance, the work of the Essex Autonomy Project.

> *when circumstances render treatment of this kind necessary as a last resort, and the treatment is subject to legal safeguards.*

Finally, it is perhaps of interest[5] to note that the Committee's Concluding Observations upon the United Kingdom as finally published 3 October 2017 contained a subtle, but important, change from the advance version commented upon in our September 2017 Mental Capacity Report. The advance version provided this:

> *Right to life (art. 10)*
>
> *26. The Committee observes with concern the substituted decision-making in matters of termination or withdrawal of life-sustaining treatment and care that is inconsistent with the right to life of persons with disabilities as equal and contributing members of society.*
>
> *27. The Committee recalls that the right to life is absolute from which no derogations are permitted and recommends that the State party adopt a plan of action aimed at eliminating perceptions towards persons with disabilities as not having "a good and decent life", but rather recognising persons with disabilities as equal persons and part of the diversity of humankind, and ensure access to life-sustaining treatment and/or care.*

The final version reads:

> *26. The Committee notes with concern that the substituted decision-making applied in matters of termination or withdrawal of life-sustaining treatment and care is inconsistent with the right to life of persons with disabilities as equal and contributing members of society.*
>
> *27. The Committee recommends that the State party adopt a plan of action aimed at eliminating perceptions towards persons with disabilities as not having "a good and decent life" and recognizing persons with disabilities as equal to others and part of the diversity of humankind. It also recommends that the State party ensure access to life-sustaining treatment and/or care.*

As explained in the September 2017 Mental Capacity Report, the underlined part of the first sentence in the original version of paragraph 27 took us into very strange and difficult territory in a case such as that of Mr Briggs; its removal (whether or not this has anything to do with the commentary we gave) undoubtedly allows the correct focus to be placed on the real issues raised by the Committee in this part of its Observations, and is therefore to be welcomed.

Assisted Decision-Making (Capacity) Act consultation

In other news from the Republic of Ireland, the consultation on the Draft Codes of Practice for Advance Healthcare Directives to accompany Part 8 of the Assisted Decision Making (Capacity) Act 2015 is now open. Details of the consultation process and the draft codes are available here, and the consultation runs until 4 May 2018.

[5] With due credit to Professor Wayne Martin of the EAP for spotting this.

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Conferences

Conferences at which editors/contributors are speaking

Law Society of Scotland: Guardianship, intervention and voluntary measures conference

Adrian and Alex are both speaking at this conference in Edinburgh on 26 April. For details, and to book, see here.

Medical treatment and the Courts

Tor is speaking, with Vikram Sachdeva QC and Sir William Charles, at two conferences organised by Browne Jacobson in London on 9 May and Manchester on 24 May.

Other conferences of interest

Towards Liberty Protection Safeguards: Implications of the 2017 Law Commission Report

This conference being held on 20 April in London will look at where the law is and where it might go in relation to deprivation of liberty. For more details, and book, see here, quoting HCUK250dols for a discounted rate.

UK Mental Disability Law Conference

The Second UK Mental Disability Law Conference takes place on 26 and 27 June 2018, hosted jointly by the School of Law at the University of Nottingham and the Institute of Mental Health, with the endorsement of the Human Rights Law Centre at the University of Nottingham. For more details and to submit papers see here.

Advertising conferences and training events

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

Our next report will be out in early May. 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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