Mental Capacity Law Newsletter May 2015: Issue 56

Capacity outside the Court of Protection

Introduction

Welcome to the May 2015 Newsletters, which are a little late, but delayed so as to be able to bring you the crucial Court of Appeal decision in Re MN, handed down on Thursday. Highlights this month include:

(1) In the Health, Welfare and Deprivation of Liberty Newsletter: a difficult decision on DOLS and Guardianship and best interests in the real world

(2) In the Property and Affairs Newsletter: when (and what) deputies can pay themselves for care and clarification as to when an LPA can be revoked on the basis of animosity between the attorneys;

(3) In the Practice and Procedure Newsletter: Re MN, setting out the boundary between the Court of Protection and the Administrative Court; revisiting litigation capacity; and transparency and the Court of Protection;

(4) In the Capacity outside the COP Newsletter: the new POST note on Vegetative and Minimally Conscious States;

(5) In the Scotland Newsletter: the importance of careful drafting when it comes to powers of attorney and an appreciation of two recently retired members of staff of the MWC.

And remember, you can now find all our past issues, our case summaries, and much more on our dedicated sub-site here.

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For all our mental capacity resources, click here. Transcripts not available at time of writing are likely to be soon at www.mentalhealthlaw.co.uk.

Editors
Alex Ruck Keene
Victoria Butler-Cole
Neil Allen
Annabel Lee
Simon Edwards (P&A)

Guest contributor
Beverley Taylor

Scottish contributors
Adrian Ward
Jill Stavert
Vegetative and Minimally Conscious States

POSTNOTE Number 489 March 2015: Vegetative and Minimally Conscious States

The Parliamentary Office of Science and Technology (POST) issued this paper in March. POST is an office of both Houses of Parliament, whose remit is to provide independent and balanced analysis of policy issues that have a basis in science and technology. The paper discusses the medical, legal and ethical challenges associated with the care of patients in vegetative (VS) and minimally conscious states (MCS) relying heavily on the prolonged disorders of consciousness (PDoC) national clinical guidelines published by the Royal College of Physicians (RCS) in 2013 (RCP Guidelines).

The POSTnote focuses its discussion on the challenges associated with adult patients in PDoC. PDoC refers to a state where a patient has wakefulness but absent or reduced awareness for more than 4 weeks. It encompasses both the vegetative state and the minimally conscious state. These challenges are said to include the lack of accurate diagnosis and prognosis in the absence of objective clinical tools or statistics, difficulties with commissioning and providing appropriate care and debates on withdrawing and withholding treatment.

Issues with diagnosis:

The paper reports that diagnosis of VS and MCS is still mainly carried out by specialist doctors and other health professionals who observe patients for behaviours that suggest awareness of self or of their environment. Misdiagnosis is said to be common (up to 43% of patients initially thought to be in VS are subsequently found to be in MCS) despite the use of several assessment tools that have been developed to improve accuracy of diagnosis (such as the SMART and WHIM tests) and the use of technologies such as fMRI (Functional MRI), EEG and DTI (diffusion tensor imaging) where appropriate. This is seen as important because misdiagnosis can have an effect on the care, rehabilitation and funding that the patients receive. The paper recommends that in order to improve diagnosis patients in MCS and VS are assessed and treated in specialist units to identify and treat reversible causes, that they are treated in specialist rehabilitation centres, provided with specialist care and re-assessed at regular intervals.

Providing and paying for care:

Although the numbers of patients with such conditions are unknown (because there is no national registry) the paper estimates that there are between 4,000-16,000 patients in VS and three times as many in MCS. It further estimates that it costs in the region of £7,500 per month to look after a patient in PVS (permanent vegetative state) and a similar amount for those in MCS. The paper states that in England the first 3-4 months of care is usually commissioned and paid for by the NHS and that thereafter care is usually paid for by local clinical commissioning groups. The paper highlights the problem with this, namely patients may require specialist treatment for longer, and conflicts can arise between those paying for and providing long term care. The paper notes that the RCP Guidelines recommend that national specialist commissioning should fund all active healthcare and that continuing healthcare should fund all long-term care costs.

1 Full disclosure: both Tor and Alex provided comments upon a draft of the paper.
Withdrawning and withholding treatment:

Decisions about when to give, withhold or end treatment are guided by the patient’s wishes (if known), professional ethics and codes of practice, and relevant legislation and case law. The paper refers to the challenge of applying these principles to patients who lack capacity to refuse treatment and about whom there often remains uncertainty about diagnosis, prognosis and the benefits of various treatments. It highlights that very few patients have made advance decisions to refuse treatment or have made a welfare LPA’s and that in these circumstances those making treatment decisions must act in accordance with the MCA in the best interests of the patient [see Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67; United Lincolnshire Hospitals NHS Trust v N [2014] EWCOP 16].

The paper cites a European wide survey that has recorded that most people would not wish to be kept alive in a vegetative or minimally conscious state. It is certainly well recorded that in most withdrawal cases the families or those close to the patient report that the patient ‘would not have wished to live like this’ [see W v M and others [2011] EWHC 2443 (Fam)].

Withdrawning Clinically Assisted Nutrition and Hydration (CANH)

The paper records that treatments to support or prolong life, such as ventilation, dialysis, or cardiopulmonary resuscitation are often withheld or withdrawn when the clinician and family are in agreement that the patient would not benefit from them. It notes that judicial approval is required for the withdrawal of CANH in all PVS cases and that the withdrawal of CANH is treated differently from the withdrawal of any other type of treatment. The reasons give in the paper for CANH being treated differently from other forms of treatment are that the mode of dying is different and that the death can be protracted and distressing for carers and members of the family to witness. I would add that withdrawing nutrition and hydration, which is seen as nurture, from a person who is otherwise in good health has an ethical and emotional dimension that sets it apart from the withdrawal of other kinds of treatment.

It should also perhaps be noted that judicial approval for withdrawal of CANH is also required for patients in MCS (COPR 2007 PD9E para 5(a) referred to by Baker J in W v M at paragraph 257

‘First, it is important to reiterate that a decision to withhold or withdraw ANH from a person in VS or MCS must be referred to the court’

Applications to the Court of Protection to withdraw CANH from patients in PVS and MCS:

The paper states that it is necessary to go to the Court of Protection to apply for withdrawal of CANH from a patient in PVS even if the families, doctors and lawyers are in agreement that withdrawal is in the patient’s best interests. As set out above it is also necessary to apply to the court for withdrawal of CANH for patients in MCS. The paper sets out the usual objections to the current procedure: delay, legal costs, and emotional costs and media attention.

It is suggested, interestingly, that if the family, clinicians and lawyers are in agreement that the patient is in PVS and that it is in the patient’s best interests for CANH to be withdrawn that the application to withdraw should be made by written submissions only (rather than written and oral submissions). This suggestion seems to have emanated from communication between the
The author of the paper and Baroness Elizabeth Butler-Sloss, the former President of the Family division who presided over a number of these cases. It is in line with the suggestion made in the seminal PVS case of *Bland* in 1993 that “similar cases should go to court until a body of experience and practice has been built up which might obviate the need for application in every case.”

It is easy to see the attraction of this idea. But it is difficult to identify how such a procedure would ensure public confidence in the judicial process, as Baker J said in *W v M*:

> ‘Provided that the privacy of the individuals involved is fully respected, it is imperative that the press should be as free as possible to report cases of this sort. The issues involved are of fundamental importance to all of us, both collectively and individually. For society as a whole, they touch upon the very challenging issues, currently the subject of much public debate, about the treatment of those suffering from severe disability, and those nearing the end of their lives. For each of us as individuals, they draw attention to the question of how we would wish to be treated should we find ourselves in a vegetative or minimally conscious state. The public needs to be informed about how such questions are resolved, be it under the advance decision procedure in sections 24 to 26 of the Mental Capacity Act or by application to the Court of Protection. It is therefore in the public interest for such cases to be reported as widely and freely as possible, provided that due respect is paid to the wishes of the family to protect their privacy.’

The Court of Protection Rules and Practice Directions are currently under review, and it is possible that consideration will be given to amending the rules and PD9E to facilitate the changes referred to above and give effect to judicial guidance set out in *W v M* and *NHS Trust & Ors v FG* [2014] EWCOP 30.

**Terminal sedation**

The paper ends by making reference to the debate over terminal sedation. It suggests that the advantages of terminal sedation would be a predictable time of death, fewer physiological manifestations and that it would enable organ donation to take place after death. It notes the opposing view centres upon the legal and ethical distinction between acts and omissions and that a number of groups are opposed to euthanasia in any context. The paper does not attempt to take the discussion any further; this is unsurprising since there does not appear to be any public appetite for such a change in the law.

> Beverley Taylor

**Rights Info**

Finally, a plug for the new site rightsinfo.org, established (with some very zippy infographics) to dispel the lazy myths about human rights. It is an excellent resource, which may – depending on what happens in the next few days and weeks – be of no little use in explaining to our new political masters what human rights have ever done for us.
Conferences

Conferences at which editors/contributors are speaking

Mentally Disordered Offenders – disposals, risk and remedies

Jill is speaking at this Legal Services Agency seminar “Mentally Disordered Offenders - disposals, risk and remedies” on 18 May in Glasgow, addressing “The Mental health Bill and Mentally Disordered Offenders.”

‘In Whose Best Interests?’ Determining best interests in health and social care

Alex will be giving the keynote speech at this inaugural conference on 2 July, arranged by the University of Worcester in association with the Worcester Medico-Legal Society. For full details, including as to how to submit papers, see here.

Editors
Alex Ruck Keene
Victoria Butler-Cole
Neil Allen
Annabel Lee
Simon Edwards (P&A)

Guest contributor
Beverley Taylor

Scottish contributors
Adrian Ward
Jill Stavert

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 Mind in return for postings for English and Welsh events. For Scottish events, we are inviting donations to Alzheimer Scotland Action on Dementia.

Click here for all our mental capacity resources
Chambers Details

Our next Newsletter will be out in early June. Please email us with any judgments or other news items which you think should be included. If you do not wish to receive this Newsletter in the future please contact marketing@39essex.com.

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Neil Allen
Annabel Lee
Simon Edwards (P&A)

Scottish contributors
Adrian Ward
Jill Stavert

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David Barnes
Chief Executive and Director of Clerking
david.barnes@39essex.com

Alastair Davidson
Senior Clerk
alastair.davidson@39essex.com

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

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

London
39 Essex Street, London WC2R 3AT
Tel: +44 (0)20 7832 1111
Fax: +44 (0)20 7353 3978

Manchester
82 King Street, Manchester M2 4WQ
Tel: +44 (0)161 870 0333
Fax: +44 (0)20 7353 3978

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

For all our services: visit www.39essex.com

Click here for all our mental capacity resources
Contributors: England and Wales

Alex Ruck Keene
alex.ruckkeene@39essex.com
Alex been recommended as a leading expert in the field of mental capacity law for several years, appearing in cases involving the MCA 2005 at all levels up to and including the Supreme Court. He also writes extensively about mental capacity law and policy, works to which he has contributed including ‘The Court of Protection Handbook’ (2014, LAG); ‘The International Protection of Adults’ (2015, Oxford University Press) and Jordan’s ‘Court of Protection Practice.’ He is the general editor of the fourth edition of ‘Assessment of Mental Capacity’ (Law Society/BMA , forthcoming ). He is an Honorary Research Lecturer at the University of Manchester, and the creator of the website www.mentalcapacitylawandpolicy.org.uk. To view full CV click here.

Victoria Butler-Cole
vb@39essex.com
Victoria regularly appears in the Court of Protection, instructed by the Official Solicitor, family members, and statutory bodies, in welfare, financial and medical cases. She previously lectured in Medical Ethics at King’s College London and was Assistant Director of the Nuffield Council on Bioethics. Together with Alex, she co-edits the Court of Protection Law Reports for Jordans. She is a contributing editor to Clayton and Tomlinson ‘The Law of Human Rights’, a contributor to ‘Assessment of Mental Capacity’ (Law Society/BMA 2009), and a contributor to Heywood and Massey Court of Protection Practice (Sweet and Maxwell). To view full CV click here.

Neil Allen
neil.allen@39essex.com
Neil has particular interests in human rights, mental health and incapacity law and mainly practises in the Court of Protection. Also a lecturer at Manchester University, he teaches students in these fields, trains health, social care and legal professionals, and regularly publishes in academic books and journals. Neil is the Deputy Director of the University’s Legal Advice Centre and a Trustee for a mental health charity. To view full CV click here.

Annabel Lee
annabel.lee@39essex.com
Annabel appears frequently in the Court of Protection. Recently, she appeared in a High Court medical treatment case representing the family of a young man in a coma with a rare brain condition. She has also been instructed by local authorities, care homes and individuals in COP proceedings concerning a range of personal welfare and financial matters. Annabel also practices in the related field of human rights. To view full CV click here.

Simon Edwards
simon.edwards@39essex.com
Simon has wide experience of private client work raising capacity issues, including Day v Harris & Ors [2013] 3 WLR 1560, centred on the question whether Sir Malcolm Arnold had given manuscripts of his compositions to his children when in a desperate state or later when he was a patient of the Court of Protection. He has also acted in many cases where deputies or attorneys have misused P’s assets. To view full CV click here.
Adrian Ward
adw@tcyoung.co.uk

Adrian is a practising Scottish solicitor, a partner of T C Young LLP, who has specialised in and developed adult incapacity law in Scotland over more than three decades. Described in a court judgment as: “the acknowledged master of this subject, and the person who has done more than any other practitioner in Scotland to advance this area of law,” he is author of Adult Incapacity, Adults with Incapacity Legislation and several other books on the subject. To view full CV click here.

Jill Stavert
J.Stavert@napier.ac.uk

Dr Jill Stavert is Reader in Law within the School of Accounting, Financial Services and Law at Edinburgh Napier University and Director of its Centre for Mental Health and Incapacity Law Rights and Policy. 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 2013 updated guidance on Deprivation of Liberty) and is a voluntary legal officer for the Scottish Association for Mental Health. To view full CV click here.