

WHY FUTILE AND UNWANTED LIFE-PROLONGING TREATMENT CONTINUES FOR SOME PATIENTS IN PERMANENT VEGETATIVE STATES (AND WHAT TO DO ABOUT IT): CASE STUDY, CONTEXT AND POLICY RECOMMENDATIONS

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ABSTRACT

In August 2017 a judge sanctioned withdrawal of clinically assisted nutrition and hydration from a patient who had been sustained in a vegetative state for twenty-three years, finding it “overwhelmingly in his best interests” for treatment to stop, allowing him to die. Injured in 1994, this patient had continued to receive life-sustaining treatment long after clinicians, and his family, had abandoned any hope for recovery and with no evidence that he would have wanted to be kept alive this way. Based on interviews with his parents, and the court hearing, we explore how it came about that he received this treatment for so long. We contextualize this in relation to our wider research about the treatment of severely brain injured patients and ask why, despite guidelines, policies and statute concerning best interests decision-making, thousands of patients in permanent vegetative states are similarly maintained in England and Wales without any formal review of whether continuing clinically assisted nutrition and hydration is in their best interests. We consider the implications for ethics, policy and practice in relation to patients with prolonged disorders of consciousness more broadly, highlighting in particular the actions that need to be taken by clinicians, inspection bodies, Clinical Commissioning Groups and Health Boards across England and Wales.

I. INTRODUCTION

The problem of futile treatment for patients in a permanent vegetative state (PVS) is often laid at the door of families who insist on life-sustaining treatments that clinicians deem inappropriate. This may arise from families’ failure to accept the devastating nature of their relative’s brain injuries or from a ‘natural instinct’ to cling to hope for recovery – or because, although they understand the clinical facts, they dispute the ‘futile’ label, believing that any life is better than none. Even if a family believes that the patient would not want to be kept alive and accepts certain ceilings of treatment (e.g. no resuscitation or no return to intensive care), they may resist cessation of other interventions - most notably clinically assisted nutrition and hydration (CANH – also known as ‘artificial’ nutrition and hydration, ANH). Such resistance is often underpinned by the powerful symbolic values associated with feeding, fear of a ‘bad death’ and doubt about – or rejection of - the ethical/legal distinction between treatment withdrawal and active euthanasia [see endnotes 1-3]

The solution is often presented as “effective communication” whereby “the medical team gives pertinent information, checks its reception, [and] takes appropriate action in order to diminish family anxiety” ([1] pp 919-920). This advice assumes, of course, that the medical team is proposing to withhold or withdraw treatment and that families are

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insisting that life-sustaining treatments are given. Such situations exist, of course, but our recent research [4] and experience in supporting family members of patients with catastrophic brain injuries [5, 6] highlights a different issue: that of medical teams who continue to deliver CANH (and other life-sustaining treatments) long after families come to believe that such treatments are unwarranted. We report on one such case here, concerning a patient who was maintained in a vegetative state for 23 years.

We contextualize this case study in relation to our broader work with 85 family members with experience of having a relative with a prolonged disorder of consciousness, and draw out implications for ethics, policy and practice. In particular, we argue that explaining the long-term futile treatment of PVS patients as due to intractable pressure from families, obscures the legal, institutional, clinical and organizational factors underpinning this state of affairs. Estimates suggest that up to 16,000 PVS patient [endnote 7] are being maintained in England and Wales today. We argue that an ethical response to this situation must go beyond a concern with family psychology and communication needs: it is imperative to address key structural issues.

II. MEDICO-LEGAL CONTEXT TO THE CASE

The patient, (we will call him G)¹ who is the focus of this article was injured in 1994. In 2017 the Court of Protection heard evidence that that he had been unconscious ever since his injury – and the judge ruled that CANH was “overwhelmingly” not in his best interests. These twenty-three years span over two decades of medico-legal development and media reporting in which the right not to be subject to futile or unwanted treatment has gained increasing attention across Europe, North America and beyond². G was injured in the UK, the year after the landmark *Bland* judgment - which ruled that feeding tubes are medical treatment and can be withdrawn if not in the patient’s best interests - indeed continuation of the treatment will, if not in the best interests of the patient, be unlawful³.

At least five similar cases had been subject to court judgments by 1999⁴, by which point G’s diagnosis of PVS (originally made in 1995) had been confirmed on several occasions. The law required reconsideration of the *Bland* principles after October 2000 in light of the incorporation of the European Convention on Human Rights into domestic law (via the Human Rights Act 1998) – in particular Article 2 (right to life). Between 2000 and 2001 Butler-Sloss J heard at least another five additional cases concerning withdrawal of CANH from PVS patients in relation to ‘right to life’, and found in each case that

¹ The patient’s full name is in the public domain. However, as his parents would have preferred his name not to be published, we have chosen to refer to him only as ‘G’ in this article. This was the initial used in the court hearing (Case No. COP 95043878).

² Highly publicized cases include: Terri Schiavo (USA), Eluana Englaro (Italy); *Re a Ward of Court (withholding medical treatment) (No. 2)*, [1996] 2 I.R. 79; [1995] 2 I.L.R.M. 401; Aruna Shanbaug (India).

³ *Airedale NHS Trust v Bland* [1993] A.C. 789; [1993] 2 W.L.R. 316

⁴ *Frenchay Healthcare NHS Trust v S* [1994] 1 W.L.R. 601; [1994] 2 All E.R. 403. *Swindon and Marlborough NHS Trust v S* (unreported - but see; *Guradian* Dec 10 1994; *Med. L. Rev.* 1995, 3(1), 84-86); *Re D (Medical Treatment: Mentally Disabled Patient)* [1998] 2 F.L.R. 22; [1998] 2 F.C.R. 178; *Re H (A Patient)* [1998] 2 F.L.R. 36; [1998] 3 F.C.R. 174

withdrawal was lawful and in patients' best interests⁵.

On the medical front, the House of Lords' Select Committee on Medical Ethics⁶ had recommended, immediately post-*Bland*, that a code of practice should be developed. A working group convened by the Royal College of Physicians (RCP) undertook a review and published the Guidelines for the Diagnosis and Management of the Permanent Vegetative State in 1996, endorsed by the Conference of Medical Royal Colleges and their Faculties in the UK⁷. These guidelines were revised and updated in 2003 [endnote 8] and again in 2013 [endnote 9]: both iterations clearly highlight ongoing life-prolonging treatment for PVS patients as futile⁸.

In 2007, the implementation of the Mental Capacity Act 2005 incorporated into statute the requirement that; "An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests" (s.1(5) MCA), and explicitly required a best interests assessment of all treatments delivered to incapacitated patients. Since then a whole raft of academic articles, training initiatives and resources have been produced to support professionals in implementing good practice and following the law relating to patients in PVS. Refinements and clarifications continue to be developed.⁹

The question we address here, then, is how did it come about that a patient who was correctly diagnosed as PVS on multiple occasions (and regularly assessed by professionals) continued to receive life-prolonging treatment for more than two decades, despite case law, professional guidelines, and statutes that should collectively have led professionals – ever since the 1990s - to the view that life-sustaining treatment was futile and not in his best interests? We will answer this question with specific reference to the particular circumstances of G's case, but the relevance of the answer goes far beyond it, insofar as it enables us to interrogate some of the structural and institutional forces that result in thousands of patients in PVS and other prolonged disorders of consciousness being maintained with life-sustaining treatment in England and Wales today, often without any consideration of the best interests of the individual.

⁵ *NHS Trust A v M, NHS Trust B v H* [2001] Fam 348; *NHS Trust v P* (unreported) see – digest [2000] All ER [D] 2363; *NHS Trust A v H* [2001] 2 F.L.R. 501; [2002] 1 F.C.R. 713; *Re G (adult who lacks capacity: withdrawal of treatment)* (2001) 65 B.M.L.R. 6.

⁶ Report of the Select Committee on Medical Ethics (1993-4, HL Paper 21-1)

⁷ see – Information from judgment of Sir Stephen Brown P in *Re D (Adult Medical Treatment)* [1998] 1 F.L.R. 411; [1998] 1 F.C.R. 498

⁸ RCP 2003 guidelines [8] say: "When the diagnosis of a permanent VS has been made ... further therapy is futile. It merely prolongs an insentient life for the patient, and a hopeless vigil entailing major emotional costs for relatives and carers" (para. 3.5). Under such circumstances, the diagnosis "should be discussed sensitively with relatives, who should then be given time to consider the implications, including the possibility of withdrawing artificial means of administering nutrition and hydration" (para 3.6).

⁹ These include forthcoming revised guidelines from the British Medical Association (due in Summer 2018) concerning clinically assisted nutrition and hydration for these (and other) patients without capacity to consent to it who may be treated long-term. Consensus statements have also recently been produced regarding the treatment of patients with devastating brain injuries in the early days/weeks (long before a 'Permanent' diagnosis can be given) e.g. stating that 'where patient-centred outcomes are recognized to be unacceptable, regardless of the extent of neurological improvement, then early transition to palliative care is appropriate' [10, p138].

III. OUR INVOLVEMENT WITH THE G CASE: SUPPORT, RESEARCH, ANALYSIS

The case history we present here is based on a three and a half hour in-depth narrative interview with G's parents (interviewed as a couple). Our understanding of what they told us is also informed by our personal involvement with the family – witnessing at first hand some of what they went through. They initially approached us for help in Spring 2017 as a consequence of our research and outreach in this area (see www.cdac.org.uk for more details about this work). We subsequently supported G's parents in obtaining (yet another) expert diagnostic opinion and helped with the legal procedures. The first author (Jenny) accompanied the parents to three best interests meetings, and we both attended the court hearing. The second author (Celia) acted as litigation friend for the patient. We have had around 30 hours of face-to-face contact with G's parents¹⁰ across a range of settings and have also spoken with his clinical and legal teams.

Alert to the difficulties of retrospective self-report data (especially covering such a long period), we have cross-checked the parents' recollections with other sources of information so as to further objectify the matter. A draft of this article was sent to various lawyers and clinicians involved in the case and we have incorporated relevant feedback and corrections. We also locate the parents' narrative in the context of our broader research with a range of families with PVS (and MCS) relatives in order to build up a multi-dimensional insight into the varied and complex factors that shapes patient pathways.

IV. RESEARCH ETHICS

The broader research programme of which this is a part has been approved by Ethics Committees at the Universities of York and Cardiff and received NHS approval from Berkshire Research Ethics Committee¹¹. Explicit (written) consent has been obtained for all direct quotations not already in the public domain. The patient's parents were offered the opportunity to give feedback on our summary of their account and they support the publication of this article and the use of their words. The patient himself lacked capacity to give consent – but his parents believe he would have accepted the importance of writing about this case.

Our involvement with G's parents included offering support and information drawn from our experience as researchers and as family members with a sister with profound brain injuries. We have described elsewhere [endnotes 11, 12] some of the ethical challenges raised by our different roles and relationships (as both 'insiders' and 'outsiders' and as both participants and as researchers immersed in a complex medico-legal context). Although this much broader experience undoubtedly informs our understanding and approach to analysing what happened, we have not explicitly drawn on it in this article. In particular, we have not used any privileged information gained as part of our role in

¹⁰ The patient's wife withdrew from involvement with G in 1997 and divorced him soon afterwards. She has not seen G, or had any involvement in decisions about him, for the last twenty years and it was not considered appropriate to contact her.

¹¹ Research Ethics Committee reference number: 12/SC/0495

advocating for the patient or his family.

V. MEDICAL ASSESSMENTS AND INTERVENTIONS: A PATIENT 'LOST IN PLAIN SIGHT'

G was 24 years old when, in November 1994, he became trapped in a machine at work. His oxygen was cut off for around 15 minutes and, when he was released from the machine, he went into cardiac arrest. He was left with severe hypoxic brain damage. He was resuscitated and rushed to hospital. Subsequent treatment included assisted ventilation and a series of surgical interventions over the first six months including tracheostomy and PEG insertion, the latter allowing G to be fed via a tube directly into his stomach. He was assessed for one year at a specialist rehabilitation centre leading to a formal diagnosis of PVS in November 1995, a year after his original injury, a diagnosis which was confirmed (after a second placement in another specialist rehabilitation centre) by expert reports in 1997, 1998 and 1999.

An insurance settlement, along with Continuing Health Care funding and extensive family input, ensured that G received excellent 24-hour care at home after his initial period in hospital and rehabilitation. Ongoing medical interventions included the provision of CANH and frequent PEG replacements, inoculations against influenza, and antibiotics for potentially life-threatening infections. He was regularly seen by a wide range of medical professionals as well as having annual assessments at a specialist brain injury rehabilitation unit and/or home visits and also reviews by the Health Board responsible for his Continuing Health Care funding.

This is not a case where the diagnosis was unclear, nor was the patient 'warehoused' without appropriate access to rehabilitation and assessment (as can happen in some cases [endnote 13].) However, in spite of all this attention, it seems that it was only after the parents raised the issue in 2016 that any professionals formally addressed the question of why ongoing life prolonging treatment was being provided to this permanently unconscious individual. This patient was, it seems, 'lost in plain sight'.

VI. THE PARENTS' EXPERIENCE: FROM HOPING FOR RECOVERY TO INITIATING DISCUSSION OF TREATMENT WITHDRAWAL

We summarise the parents' account of their experience in relation to: (a) the initial hospital admission; (b) the next two-and-a-half years before they began caring for their son at home; (c) two decades of home care; (d) the final 18 months after they raised the question of CANH withdrawal.

A. *The Early Weeks (November/December 1994)*

The parents talk about their son's initial period in intensive care and high dependency as a time of shock, hope and uncertainty: "*We lived in the hospital... praying please God, please, please God, let him breathe, let him be okay*". As is typical of many families whose relatives survive only to be left in long term vegetative or minimally conscious states [endnotes 14, 15], G's parents now realise that they did not have any understanding of the possible outcomes e.g. that their son could breathe but still not be "okay".

As far as we can tell from the parents' memories of what happened, no reasonable efforts were made to communicate with them about G's prognosis or what his future might hold - although obviously their experience may not reflect what clinicians intended or thought they were doing at the time. The parents recall just one occasion where they overheard some discussion about whether life-prolonging interventions should be pursued: a surgeon asked G's wife what she would want to happen if anything went wrong in theatre. She replied "*Of course I want to save him, he's only twenty-four... That was said in front of us, that we witnessed," says G's father, "*but there was nothing else*". They subsequently encountered that same surgeon outside the hospital lift. G's father thanked him for doing the surgery, "*but he tore a strip off me and basically said that we'd be sorry*". In retrospect they believe there must have been further conversations between this doctor and their son's wife, and that the doctor wrongly assumed that the whole family was resisting his advice not to pursue life-prolonging interventions. However, they do not recall ever having been invited to contribute to any such discussion and did not feel that the surgeon's interaction with them outside the lift had offered an opportunity to explore options.*

B. The First Two and a Half Years (Late 1994 to Mid-1997)

Just before Christmas 1994 their son was moved from the hospital to a specialist rehabilitation centre where he stayed for over a year. Again, his parents cannot recall any formal discussions about the value (or not) of life-prolonging interventions. There is just one passing remark that sticks in their minds: a nurse said, "*you've had a bereavement, you should be having counselling*". G's mother was shocked by the clear message that "*we'd lost him, the G we knew,*" but says that none of the medical staff actually sat down and talked them through their son's prognosis or the decisions that needed to be made. If, in fact, efforts *were* made to communicate with G's parents about these issues such efforts were clearly not successful.

After more than a year in the rehabilitation centre, G was discharged to the care of his wife. His parents were "*petrified*" and could not accept the implication that "*there was nothing more they [the doctors] could do*". They still hoped for recovery:

"I remember the doctor saying that when he comes home there'll be stimulation, cooking smells, the vacuum cleaner going, that this could stimulate G perhaps to becoming aware." (Mother)

They were also encouraged by the 'stimulation kit' they were provided with – including blocks of wood (to bang either side of G's head), sandpaper to rub on his skin, and bottles of smells to stimulate his senses.

C. Two Decades of Caring at Home (1997-2017)

In 1997 their son was provided with a temporary placement in a second specialist centre for yet more assessment. It was after this that G's wife decided to stop looking after him at home and his parents took over. They were given copies of reports clearly stating that G was in a permanent vegetative state - PVS, but say they tried to ignore this: "*P, V, S – three letters we never wanted to utter ourselves to anybody*".

In any case, documents produced as part of compensation settlements commonly incorporate unquestioned assumptions about continuation of life-prolonging treatment: there is often no consideration of treatment-withdrawal, nor any suggestion that the treatments provided might be time-limited. Instead, they presume that life will be sustained and are oriented towards the nature and cost of the care package. G's parents were left clinging to hope ("*like the miracles you read about in the newspaper*") and tried to imagine that their son had some level of consciousness. They encouraged his care team to do the same:

"He looks as if he's conscious, doesn't he? ... [We'd say] 'oh look, he's looking at you'. And we also encouraged that with [the carers], in order to have the best care for C, you know, so that he was really being looked after, be it just his body." (Mother)

Gradually, however, "*we realised we weren't seeing any change ... there was just this for him. This was his life – no life at all really*". They came to believe that "*no-one would want this*" and reflected on the contrast between his current existence and everything their son had once valued - his love of socializing, commitment to community charities and the fact that he had put thought into what he wanted after he had "gone" e.g, he carried an organ donor card and had taken out life insurance to protect his wife's financial future. Although now certain that he would not have wanted to be kept alive in his current state, "*we didn't know there was any option*" (Father); "*no one has ever said, 'Look, there is another path for [him], he doesn't have to stay like this'*" (Mother).

After some years (they estimate around 10 years after their son's initial injury), the parents nervously initiated a discussion of ceilings of treatment by asking for 'no return to hospital' and 'Do Not Attempt Cardio-Pulmonary Resuscitation' to be put on G's records. This was done but it seems that none of the clinicians looking after G responded by inviting a review of other life-prolonging interventions – in particular ongoing clinically assisted nutrition and hydration.

D. The Final 18 Months

It was in January 2016 that G's parents confronted the possibility of withdrawing his feeding tube as an option. Such consideration was prompted not by information or support from *clinicians* but by reading a magazine article about another family's experience of this being done for a PVS family member. The parents raised the possibility of CANH-withdrawal with their son's GP who, although initially appearing "startled", offered his full support. The GP moved quickly to refer G to a palliative care specialist who visited within a few days, reviewed G and put ceilings of treatment in place in respect of antibiotics. Some of the front-line staff who had been caring for G over many years apparently supported this move and were relieved to see such decisions enacted, but others resisted it – and were very distressed.

From this point the case moved slowly towards court, though it was 18 months after this conversation with the GP before it actually went before a judge¹². Although a

¹² We have written elsewhere about the delays typically introduced at this stage [endnotes 4, 5]. In this case the first up-to-date independent assessment was not provided until January 2017; it is unclear

solicitor was instructed by the Health Board in early 2016, the application was not lodged until summer 2017. Most of this delay was caused by the process of getting the evidence for the application together – including getting two more, up-to-date, expert assessments. The second report was considered advisable after two carers – opposed to stopping treatment - raised the possibility that G had some awareness, citing examples such as a startle response to loud noises and moving eyes in ways which, they believed, were deliberate actions in response to sounds. It is quite common for carers to raise such concerns at the point at which treatment-withdrawal becomes an issue. The second expert assessment in 2017 confirmed once again - for the sixth time since his injury – that G was in a PVS; systematic testing of some of the behaviours reported by carers found these to be reflexive or spontaneous, i.e random, rather than prompted by external stimuli, and the consultant concluded that there was no evidence of any conscious awareness.

When G's parents initially approached us for support (in 2017, between the first and second additional independent diagnostic assessments), they felt that life-prolonging treatment had continued for far too long and were frustrated and distressed by the time it was taking to get the case to court. They looked back over what had happened in the preceding two decades and expressed great concern:

"All we're doing is looking after G's body. We've just accepted it over the years. But now I feel we've not done enough. We've just cared for him, not thought about what we should do for him."
(Mother)

G's father added: *"I worry that we have been negligent"*, but he also drew attention to the responsibility of clinicians to raise CANH-withdrawal.

"We were going over for a yearly checkup at [the specialist centre]. They'd check 'What's his medicine?', 'What's his weight?'. And we'd try with the awareness kit: sandpaper, oils, wool. And the doctor said 'keep on doing that if it keeps you happy but don't beat yourself up'. He obviously knew – but still nothing was said. They probably thought we were in denial and we probably were. But doctors have these seminars – they have research papers come through – shouldn't they have known? Shouldn't they have said something? Why didn't anyone say anything?" (Father)

VII. DISCUSSION AND RECOMMENDATIONS

It seems that there were significant failures to follow relevant case law, guidelines and statute in this case. These apparent failings date back initially to the 1990s: there was no formal consultation with the parents when clinicians made decisions about life-prolonging treatment while their son was in hospital or when he was subsequently transferred to specialist assessment settings. Even once the PVS diagnosis was confirmed for the fourth time (in 1999) and G's parents took on the responsibility of caring for him at home, clinicians apparently still failed to initiate such discussions with

why this took so long given that the parents had raised the issue a year earlier. The second assessment came six months later, delayed, in part, by the fact that the most relevant specialist service had a long waiting list (especially for patients with tracheostomies). This was eventually resolved by transferring G to yet another specialist centre (the third specialist unit to take him – and one outside the usual area) – a positive example of flexible responses to circumvent the possibility of drawing out the whole process still further.

them – and those responsible for determining their son's best interests (which includes a range of health care commissioners/providers/inspectors) – seem not to have made any such determinations.

A. Organisational Communication, Missed Opportunities and Treatment-By-Default

One issue is apparent, failures in communication between the different professionals and organisations involved in the 1990s (such that the repeated diagnoses of G as being in a PVS) may not have been communicated to the commissioning/funding body: if this is so then there cannot have been appropriate consideration of G's best interests, including (but not limited to) the question of whether continuing CANH was in his best interests. It seems no one joined the dots between the multiple confirmed PVS diagnoses and best interests decision-making.

From the parents' reports it is also evident that opportunities to question the assumption that treatments would be provided indefinitely were missed at routine clinical interventions and at regular reviews over the years that followed. These opportunities included frequent PEG replacement by a specialist who regularly came to their home, the annual reviews when G was taken to the specialist rehabilitation centre (assessments which went on for many years), and also the annual reviews carried out by the Health Board assessing his care needs. Another opportunity for professionals to comply with guidelines and statute was missed when G's parents initiated discussions about whether some life-prolonging interventions (e.g, CPR, returns to hospital) could be withheld/withdrawn. At that point, nobody seems to have used the opportunity to raise the issue of other life-prolonging interventions – in particular CANH.

Overall, what we see in this case is that instead of treatments being decided by reference to G's best interests, an entire infrastructure and reams of official documentation supported treatment-by-default. This was implemented in the complete absence of any evidence that it was in his best interests, and in the face of ample evidence that it was futile and possibly unlawful – and long after his parents had come to believe he would not have wanted his life prolonged.

G's story is exceptional for the length of time he was sustained in PVS - and also for the fact that court proceedings were finally initiated which allowed his death. But the failings in G's case echo what we have found in our wider research [endnotes 3-6]. Families, and staff too, feel trapped in a system of 'care delivery' which seems to have its own logic and momentum. It seems that some of the health care workers involved in G's care had been deeply troubled by the situation but did not know there were options, or did not feel they had the skills to challenge what was happening, or felt it was not their place to raise the question of whether or not continued life-prolonging treatment was right. Others may have simply found the option of CANH-withdrawal ethically unacceptable. Even once the parents initiated the discussion and the Health Board started proceedings there was still an additional delay before the case reached court. As a result of all these factors G's human right not to receive futile and unwanted treatment was breached for decades.

B. Lessons Around Support/Training Needs

There are important lessons to be learned from G's case (and other cases of prolonged disorders of consciousness more generally across the UK) including the following:

- a. It is essential that family and staff understand the medico-legal context and have access to high-quality information about clinical, social and ethical issues concerning treatment of this patient group
- b. Families must be given appropriate information and support – including support over time and across different settings (including when caring for a patient at home)
- c. Staff working in this area may need special training and support to address their own concerns and to develop the skills to have difficult conversations.
- d. It is also important that staff have training and understand the responsibilities of their role (which includes acting in the best interests of patients as laid out in the Mental Capacity Act 2005, its associated Code of Practice, and in professional guidelines).

But repeated calls for such lessons to be learned - and the production of materials to support best interests decision making¹³ - seem to have produced only very slow change. We think it is time to address key structural problems including the legal context and how care is inspected, commissioned and delivered.

C. The Legal Context

One such structural problem - the long-standing apparent requirement for judicial review of these treatment decisions in England and Wales - is already being addressed. We have discussed elsewhere the ways in which the belief – buttressed by Court of Protection Practice Direction 9E - that court applications are mandatory before CANH can be withdrawn from patients in permanent vegetative and minimally conscious states has acted as a deterrent to withdrawal [endnotes 4, 5]. Our analysis has highlighted how this can mean that many patients have continued to receive treatment that is not in their best interests either as they await court hearings, or because their case is not brought before the court at all. In an important recent development (which came, on 1 December 2017, just too late for G) the Court of Protection Rules Committee withdrew Practice Direction 9E.

This move away from the apparent need for court approval has also been clear in recent legal judgments.¹⁴ A series of judges have made statements that there is no requirement

¹³ For examples of such resources see <http://cdoc.org.uk/publications/resources-for-families-and-practitioners/>

¹⁴ *NHS Trust v Mr Y (By his Litigation Friend, the Official Solicitor) and Mrs Y* [20017] EWHC 2866 (QB) (available at www.bailii.org/ew/cases/EWHC/QB/2017/2866.html); *Director of Legal Aid Casework & Ors v Briggs* [2017] EWCA Civ 1169; [2018] 2 W.L.R 152 (available at: www.bailii.org/ew/cases/EWCA/Civ/2017/1169.html); and *M v A Hospital* [2017] EWCOP 19; [2018] 1 W.L.R 465. (available at:

on treating clinicians to seek the court's prior approval to withdraw CANH for a patient in PVS or MCS where existing professional clinical guidance has been followed and where the treating team and those close to the patient are all in agreement that it is not in the patient's best interests to continue such treatment. A joint statement by the British Medical Association, the Royal College of Physicians and the General Medical Council underlines this point [endnote 19] and the Supreme Court hearing on this matter (Re. Y, UKSC 2017/0202) in February 2018 should remove any final doubt about the circumstances under which court applications must be made before CANH can be withdrawn.

D Ensuring that Best Interests Considerations are Integrated Into the way Care is Inspected, Commissioned and Delivered

Although removal of the perceived need to go to court will be an important step towards getting rid of one source of delay, it is clear that this will not completely resolve the problem of treatment-by-default for patients in permanent vegetative states – or indeed in other prolonged disorders of consciousness e.g, vegetative states that are not yet diagnosed as 'permanent' or minimally conscious states. Our analysis of the G case (and other cases we have examined) shows that additional changes are required to ensure that all decisions about these patients are the outcome of robust best interests procedures.

We recommend that organisations responsible for *inspecting* care (e.g. the Care Quality Commission in England and the Healthcare Inspectorate in Wales) should hold those responsible for providing care accountable for high quality best interests decision-making. This could include routinely asking for evidence of best interests decision-making for CANH for patient in a prolonged disorder of consciousness.

We also recommend that those responsible for *funding and commissioning* care (Clinical Commissioning Groups in England; Health Boards in Wales) should take responsibility for ensuring that all treatment they commission is in the best interests of the patient – and require this to be clearly supported by the correct documented evidence. Alongside this, it is essential that they provide the appropriate resources to allow this to happen, including access to independent expert second opinions as required, and it is vital to ensure that CCGs and Health Boards know where patients are – and that information is exchanged and their treatment is appropriately co-ordinated.

Despite some reorganization of the health service and despite new guidelines and procedures, it is clear that what happened to G is probably still happening to other PVS patients today. Although Health Boards and Clinical Commissioning Groups provide the funding for treatment of PVS/MCS patients, it seems they do not know how many PVS (or MCS) patients are being maintained on their books. Clinicians regularly tell us that this is the case and this is supported by the results of a Freedom of Information request: only 62 of the 238 health authorities approached by the BBC could provide any

www.bailii.org/ew/cases/EWCOP/2017/19.html).

information on how many such patients were their responsibility [endnote 16]. In addition, Health Boards and CCGs do not have any process of monitoring or assessing this ongoing treatment.

Change is urgently needed to ensure the appropriate care for patients like G. On the basis of our analysis of this case (and others), we support recent recommendations [endnote 17] for implementation of a clinical pathway based on the principles embodied in the Mental Capacity Act 2005 combined with the use of time-limited treatment-trials. This includes the following recommendations:

Service commissioners should create and fund a centralized register, and require all services to put people entering (or already in) a prolonged disorder of consciousness on this register.

Patients must have access to *the appropriate level* of diagnostic and prognostic expert assessment. By 'appropriate' level of diagnosis/prognosis we mean to the level of precision or (un)certainly that *the patient* would have wanted to ensure their wishes can be respected in best interests decisions about them. This does not necessarily mean fine-tuning the prognosis indefinitely but does mean access to the best high-quality information available at the time.

Patients must have access to *timely* assessment and reassessment. By 'timely' we mean as specified in the latest guidelines (e.g. RCP (2013) at time of writing, and the new BMA guidelines due out in Spring/Summer 2018).

Each patient (and their family) should have an assigned care coordinator, providing continuity and following the patient over time and across diverse services: this person's role could include high-level understanding of the issues for VS/MCS patients, responsibility for ensuring that accurate information is available to the right people and appropriately entered into decision-making processes, and support for the family in navigating the systems responsible for the care of their relative. [See 18]

There needs to be a clear line of responsibility for decision-making. Although – according to s. 5 of the Mental Capacity Act – everyone who “does an act in connection with the care or treatment of another person [who lacks capacity to consent]” is responsible for ensuring such treatment is in the patient's best interests. This does not seem to be happening in practice. Currently there seems to be some doubt about who is responsible for the decision to continue administration of CANH for patients in prolonged disorders of consciousness and the responsibility for the act of giving the treatment is, in practice, diffused between different persons/bodies, none of whom may 'own' the decision. The responsible clinician for patients cared for at home (like G) or in long-term care homes is often considered to be the GP, who may see the patient infrequently and only when they become ill (e.g. with a lung infection): the GP may not feel they have the relevant specialist expertise or authority to question ongoing CANH and even the clinician replacing a PEG may not take responsibility for a best interests assessment (although they, of course, should). The funding/commissioning organisation is clearly identified as carrying key responsibility in the RCP guidelines [9] but often sees themselves as dependent on medical advice as to what treatments should be funded and do not in practice seem to necessarily apply best interests considerations to that advice. Often both health care staff and organisations abdicate responsibility, quite wrongly, waiting for 'the family' to raise questions about withdrawal.

A key underlying necessary condition here is initiating and following best interests decision-making procedures for all patients in prolonged disorders of consciousness. We recommend that commissioners should require services to hold regular best interests meetings that are properly, skillfully and sensitively conducted, and documented to comply with the Mental Capacity Act. This includes:

Regular best interests meetings should be backed up by appropriate information for, and support for families (and staff as necessary) - including access to independent second opinions as appropriate.

Staff should not rely on consulting just one person acting as 'next of kin'. Instead, as specified by the MCA Code of Practice, the decision-maker has a duty to consult (1) anyone named before loss of capacity (2) anyone caring for the person (3) close relatives and friends and (4) any legally appointed attorney or deputy (MCA Code of Practice, para 5.49).

Meetings should explicitly address what the patient would have wanted (not just asking family members what *they* want, or asking them to make the decision)

Such best interests meetings should explicitly address whether or not each and every treatment is in the patient's best interests – including asking that question about CANH

It should be made clear that discussing treatment-withdrawal options is not about 'abandoning' the patient or withdrawing 'care': it is about ensuring appropriate, person-centred care. The discussion should include information about palliative pathways and accurate information about other families' experiences [20].

Best Interests decision processes and outcomes should be properly documented

We agree with Professor Derick Wade that if commissioners: "funded a register and only paid providers if appropriate standards derived from national guidelines were met, then the situation could be transformed" [endnote 14].

VII. CONCLUSION

In conclusion, patients in prolonged disorders of consciousness (whether in a prolonged coma, vegetative or minimally conscious state) are extremely vulnerable and there are many challenges confronting their families who are faced with excruciating loss, accompanied by early prognostic uncertainties and conditions which are very difficult to understand. Families have to negotiate complex issues relating to their own wishes, their relative's prior (and possible/imagined current) wishes and the likely persistence of hope for recovery fuelled by media (mis)representations and hype around scientific 'breakthroughs' and nurtured by the well-intentioned impulses of friends and acquaintances, and some health care staff whose motivation is to offer comfort. The healthcare service needs to provide a high level of care, support and governance to ensure that patients' best interests are served and to address the serious problem of futile/unwanted treatment delivered in England and Wales to some of this patient group. It should not be left to families – like G's parents here, or the wife of minimally conscious Paul Briggs [6] - to raise the question of, or advocate for, treatment withdrawal.

Dealing with this problem needs to move beyond scapegoating families as the source of the problem – or a focus on simply providing information and support to them (although this is a crucial part of the jigsaw) - and towards a recognition that the institutionalized provision of long-term treatment-by-default normalizes sustaining life in PVS making it difficult for families (or staff) to consider alternatives [21].

What happened to G, and to his family, is a stark illustration of what can go wrong for years, or even decades, when the system fails a patient. As his parents comment, if

lessons can be learned from his case, that is one of the few things that can mean that the suffering and the futility of it all is more than “just a waste”. We hope that the analysis presented here, and suggestions for policy/practice change can be part of G’s legacy.

Postscript:

Organisations involved in G’s case have responded proactively to the concerns raised in this article. An independent review of his notes has been commissioned and there are plans to create a working group to review current guidance and pathways for similar patients.

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We would like to thank G’s parents for their willingness to share their experience and for their consent to use their words in this article. We would also like to thank some of the professionals involved for reviewing and commenting on our account of what happened and our analysis of the implications.

Conflict of Interests Statement:

We have family experience of catastrophic brain injury and prolonged disorder of consciousness. The second author acted as litigation friend for the patient in this case.

Note: Our research has been translated into a multi-media online resource about family experience of having a severely brain injured relative. You can see filmed interviews with other families like G’s at

www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/overview.

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