



Commentary

Withdrawal of Life-Sustaining Treatment in Prolonged Disorders of Consciousness

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ABSTRACT

Decisions to withdraw clinically assisted nutrition and hydration from patients with prolonged disorders of consciousness sit at the intersection of diagnostic uncertainty, contested procedural safeguards, and difficult questions about whose values should govern an incapacitated patient's fate.

This commentary examines the 2018 shift, most visible in England and Wales, away from mandatory judicial approval of uncontested withdrawal decisions, and the divided reaction it has produced among clinicians, lawyers, and bioethicists.

It then surveys evidence that behavioral diagnosis of vegetative versus minimally conscious states remains error-prone, and that functional neuroimaging has revealed covert awareness in some patients previously judged unresponsive, complicating the evidentiary basis for withdrawal decisions.

We further examine the empirical and philosophical literature on reconstructing an incapacitated patient's likely preferences, and engage with the disability-rights critique that best-interests reasoning in this field has too readily absorbed contestable quality-of-life judgments.

We conclude that current safeguards -- second opinions, best-interests panels, family consensus, and occasional judicial review -- remain defensible only as imperfect compromises under genuine diagnostic and moral uncertainty, not as a settled resolution of the underlying ethical dispute.

Keywords: disorders of consciousness; withdrawal of treatment; end-of-life decision-making; best interests; clinical ethics

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INTRODUCTION

A patient in a prolonged disorder of consciousness

occupies an unusually difficult ethical position: they are alive, often breathing without assistance, sometimes tracking movement with their eyes, and yet

unable to communicate a preference about anything, including whether they wish to go on being kept alive by a feeding tube. Clinicians distinguish between the vegetative state (now more often called unresponsive wakefulness syndrome), in which wakefulness persists without any behavioral evidence of awareness, and the minimally conscious state, in which awareness is present but fluctuating and often minimal. Both are grouped under the umbrella term "prolonged disorders of consciousness" once they persist beyond the acute recovery window, and both raise the same underlying question with different degrees of urgency: when, if ever, is it right to withdraw clinically assisted nutrition and hydration, or other life-sustaining treatment, from someone who cannot say what they want [1]. Cross-cultural work on how clinicians and families weigh notions of sacredness and human dignity in these decisions has shown that the answer is not purely a matter of clinical prognosis; religious and secular framings of what a body owed to a dying or unconscious person diverge in ways that shape the decision as much as any diagnostic finding does [2].

The ethical debate has never really been about whether withdrawal can be permissible in principle -- most jurisdictions and most bioethicists accept that it can -- but about who should decide, what evidence should weigh in the decision, and how much the legal system should insist on external review before life is allowed to end. The past decade has sharpened rather than resolved these questions, partly because diagnostic tools for detecting residual awareness have improved, partly because several jurisdictions have relaxed the requirement that a court authorize withdrawal, and partly because litigated cases keep surfacing tensions that abstract principle glosses over. This piece surveys where that debate now stands: the shift away from mandatory judicial oversight, the persistent problem of diagnostic uncertainty, the difficulty of reconstructing what an unconscious patient would have wanted, and the disability-rights critique that some of this literature has been too quick to dismiss.

THE RETREAT FROM MANDATORY COURT OVERSIGHT

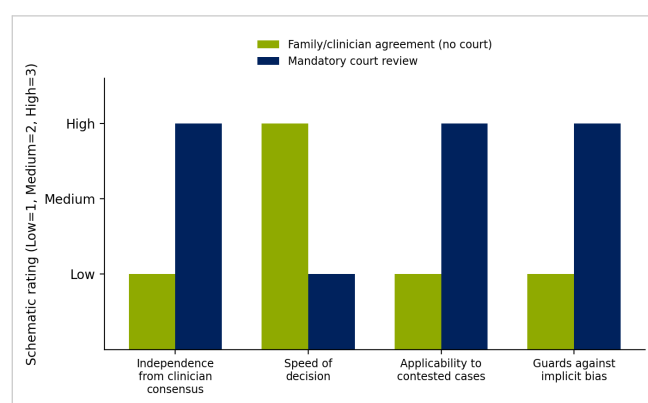
For much of the modern history of this issue, jurisdictions with a common-law tradition required that a court approve any decision to withdraw clinically assisted nutrition and hydration from a patient in a vegetative or minimally conscious state, even when the patient's family and treating clinicians were in full agreement. That changed in England and Wales in 2018, when the Supreme Court held in a case widely referred to by the abbreviation *Re Y* that no such application is legally required where the relevant guidance has been followed and there is no dispute among the people involved in the patient's care [3]. The court reasoned that mandatory judicial review served no protective function once professional

guidelines already required an independent second clinical opinion and a formal best-interests process, and that inserting a court hearing into every uncontested case both delayed a decision that families found agonizing to sustain and treated withdrawal as inherently more suspect than other high-stakes medical decisions made without judicial sign-off [4].

Table 1. Procedural models governing withdrawal of clinically assisted nutrition and hydration in prolonged disorders of consciousness, compared by required sign-off and treatment of disagreement.

Model	Required sign-off	How disagreement is handled
Family/clinician agreement (post- <i>Re Y</i> default)	Treating team plus independent second clinical opinion; family concurrence	Any party's objection triggers referral to the Court of Protection
Mandatory judicial review (pre-2018 English practice; still used elsewhere)	Court approval required in every case regardless of agreement	Adjudicated directly by the court as part of the standard process
Multidisciplinary/ethics committee model	Institutional ethics committee review alongside family consultation	Escalated to committee majority view or, failing that, external mediation
Religious or community authority model	Family consensus informed by religious or communal guidance	Resolved through religious authority or family elder consultation

Figure 1. Schematic comparison of family/clinician agreement versus mandatory court review across four dimensions relevant to the ethical debate discussed in the text (illustrative, not derived from a single empirical study).



Reaction to this shift split along a familiar fault line. Supporters argued that it corrected an anomaly: no other momentous medical decision, including withdrawing ventilation from a patient with catastrophic brain injury who is not in a vegetative state, had ever required court approval by default, so singling out prolonged disorders of consciousness for special judicial scrutiny was inconsistent and, in practice,

imposed real costs on grieving families with no corresponding safeguard [5]. Critics countered that removing the court from the process removes the one participant in the decision who has no institutional or emotional stake in the outcome, and that "doctors and family agree" is a weaker safeguard than it sounds, since family members are often exhausted, distressed, and reliant entirely on the same clinical team's framing of prognosis; on this view, the presumption in favour of preserving life is a substantive legal principle, not a procedural formality, and substantive principles are exactly the kind of thing an independent tribunal exists to police [6]. A parallel debate has played out through comparative case reports, including one recent account of a UK case examined alongside cross-jurisdictional and Islamic law perspectives, which found that even jurisdictions without a common-law tradition of judicial pre-approval have developed their own informal checks -- religious authority, multidisciplinary ethics committees, family consensus requirements -- that do some of the same work the English courts used to do by default [7]. Analysis of the court's historical role prior to *Re Y* had already flagged this tension, arguing that judicial involvement, whatever its costs, functioned as a check on the risk that professional consensus about a treatment's futility could harden into practice faster than the underlying prognostic evidence warranted [8].

Table 1 summarizes how the main procedural models compare on this dimension: who must sign off before nutrition and hydration can be withdrawn, and what happens when family and clinicians disagree. Figure 1 places the same three approaches on a schematic axis of procedural safeguard versus practical burden, illustrating the trade-off this section has described -- every model that adds an external check also adds delay and cost, and none of the three eliminates the risk of error entirely.

DIAGNOSTIC UNCERTAINTY AND THE LIMITS OF THE BEDSIDE EXAM

Nearly every ethical argument in this area assumes that clinicians can reliably tell a vegetative patient from a minimally conscious one, and that assumption is shakier than clinical practice sometimes acknowledges. Bedside behavioral assessment, still the most widely used diagnostic method, has a documented history of misclassifying patients who in fact retain some awareness, particularly when assessments are brief, infrequent, or conducted by staff without specialist training in standardized scales [9]. The consequences of that error run in only one direction that matters ethically: a patient wrongly judged vegetative when they in fact have some residual awareness is at risk of having treatment withdrawn, or simply not escalated, on the basis of a diagnosis that understates what they can perceive and, potentially, suffer [10].

Functional neuroimaging has offered a partial

corrective. Landmark work using functional MRI to detect willful modulation of brain activity in response to spoken commands demonstrated that a meaningful minority of patients who appear entirely unresponsive at the bedside can nonetheless generate reliable, command-following neural responses -- evidence of a kind of covert awareness invisible to behavioral testing alone [11]. That finding reframed the ethical stakes of the diagnostic question: if some patients believed to lack awareness in fact retain it, then decisions about withdrawing treatment, and indeed decisions about withholding pain relief or including the patient in ordinary bedside courtesies, may be resting on a false premise for an unknown fraction of this population. Public reaction to the prospect of communicating with such patients via neuroimaging has itself become a subject of study, and it is not straightforwardly supportive of aggressive life-prolongation; commentators surveying public discourse on this question found substantial concern about the burden of prolonged uncertainty for both patient and family, alongside worry that misdiagnosis could lead in either direction -- premature withdrawal or unwarranted prolongation of a state the patient would not have chosen [12]. A more recent framework for using neuroimaging findings to support, rather than replace, supported decision-making for patients with covert awareness has tried to occupy a middle position: treat a positive neuroimaging result as evidence to be weighed by the same best-interests or substituted-judgment process already in use, not as a communication channel sufficient on its own to authorize or block withdrawal [13]. Broader neuroethics scholarship has traced how these diagnostic developments have reshaped the field's conceptual vocabulary over roughly two decades, from a relatively binary vegetative/conscious framework toward a spectrum model that resists easy translation into legal categories built for bright lines [14].

RECONSTRUCTING WHAT THE PATIENT WOULD HAVE WANTED

Even when diagnosis is not in doubt, the harder ethical work is reconstructing what a patient who can no longer speak for themselves would have chosen. Advance directives specific to prolonged disorders of consciousness remain rare; most people who complete a living will do so with terminal illness or acute critical care in mind, not the specific, comparatively unusual scenario of years-long unresponsive wakefulness, and clinicians report that conversations about this possibility are seldom had before the injury that produces it [15]. In the absence of a written directive, decision-makers fall back on substituted judgment -- an attempt to infer what the patient themselves would have chosen based on prior statements, values, and behavior -- or, where that inference cannot be made with any confidence, a best-interests standard applied by family and clinicians together.

A recent systematic review of the empirical literature on reconstructing treatment preferences in this population found that family members' accounts of what the patient "would have wanted" are shaped as much by the family's own coping needs and moral framework as by any specific statement the patient made while competent, and that formal tools for eliciting these preferences remain underdeveloped relative to the stakes involved [16]. Philosophical work on precedent autonomy has pressed the deeper question of whether a pre-injury preference should even govern a post-injury patient who, by hypothesis, no longer has the same psychological continuity with the person who expressed it -- an unresolved puzzle that predates disorders of consciousness specifically but bears on it with particular force, since the interval between expressed preference and applied decision can run to years or decades [17]. General literature on the ethics of surrogate decision-making has documented a related and pragmatic problem: surrogates asked to project themselves into the patient's situation frequently substitute their own values for the patient's, a substitution that is difficult to detect from outside the family and harder still to correct once a decision has been reached [18]. Cambridge Quarterly of Healthcare Ethics has recently extended this inquiry to the harder case of a patient who retains some consciousness but lacks capacity, arguing that best-interests reasoning applied to a conscious, incapacitated patient carries ethical weight that a purely vegetative case does not, precisely because such a patient may have some experience of the decision being made about them [19].

THE DISABILITY-RIGHTS CRITIQUE

A distinct line of criticism, sharper in tone than the procedural debates above, argues that this entire body of bioethics literature has too readily accepted a background assumption that life with a severe disorder of consciousness is a state from which death is a reasonable, even humane, escape. Disability-rights scholars reviewing decades of vegetative-state jurisprudence have argued that courts and clinicians alike have imported unexamined quality-of-life judgments into supposedly neutral best-interests reasoning, judgments that would be recognized as discriminatory if applied to conscious people with equally severe physical disabilities [20]. On this view, the presumption in favour of life that some legal commentators treat as a formal safeguard is doing real ethical work precisely because it resists the slide from "this person cannot recover the life they had" to "this person's continued existence has no value," a slide the disability-rights critique regards as neither logically necessary nor ethically innocent.

This critique does not map neatly onto the procedural debate over judicial oversight discussed earlier -- one can favor court review specifically because one shares this concern about implicit bias in best-interests reasoning, or one can favor it for entirely separate

reasons about institutional checks and balances. What the critique does add is a reminder that the diagnostic and procedural questions this literature spends most of its attention on are not ethically self-contained; how clinicians and family members answer them is shaped by contestable assumptions about which lives are worth continuing, assumptions that deserve scrutiny rather than being treated as settled background.

END-OF-LIFE CARE AFTER THE DECISION IS MADE

Comparatively little of the bioethics literature on this topic addresses what happens clinically once a decision to withdraw has actually been reached, though this has begun to change. An eight-year cohort study of end-of-life care following withdrawal of life-sustaining treatment in patients with prolonged disorders of consciousness found considerable variation in symptom management practice, sedation protocols, and family support during the period between withdrawal and death, and argued that this phase deserves the same ethical and clinical attention as the decision that precedes it, since a poorly managed dying process can itself become a source of the family distress that shaped the original best-interests deliberation [21]. Family-interview studies conducted around court applications for withdrawal, before *Re Y* removed the requirement for most cases, documented similar themes: families frequently described the process itself, independent of its outcome, as protracted and painful, which is part of the empirical basis later cited in support of removing mandatory judicial review [22]. Earlier interview work with families who had withdrawn or continued artificial nutrition and hydration for a relative in a minimally conscious or vegetative state found that the emotional burden of the decision persisted regardless of which choice the family made, complicating any simple assumption that avoiding withdrawal is always the more comfortable path for those left to live with the outcome [23]. Clinical reviews of the practicalities of withdrawing nutrition and hydration in this population have likewise emphasized that "withdrawal" is not a single act but a clinical process requiring its own standard of care [24], a point echoed in commentary questioning whether physicians alone, without a formal multidisciplinary or ethics-committee structure, should be the ones adjudicating genuinely contested cases at the bedside [25].

CONCLUSION

The ethics of withdrawing life-sustaining treatment from patients with prolonged disorders of consciousness has moved past the question of whether withdrawal can ever be justified and settled into a harder set of disputes about process, evidence, and the values smuggled into supposedly neutral clinical judgments. Removing the requirement for court approval in uncontested cases has reduced one kind of burden on families while removing a safeguard that

critics argue was never merely procedural. Advances in functional neuroimaging have complicated the diagnostic picture in ways that cut both toward more caution about withdrawal and toward better-supported decision-making for patients with covert awareness, without resolving which of those pulls should dominate in a given case. The literature on reconstructing patient preferences after the fact remains thinner than the stakes warrant, and the disability-rights critique of this entire field deserves more sustained engagement than most of the procedural literature has given it so far. None of this suggests that current practice is unworkable, but it does suggest that the safeguards this field relies on -- second opinions, best-interests panels, family consensus, occasional judicial review -- need to be understood as imperfect compromises under real diagnostic and moral uncertainty, not as a settled solution to a problem that has, in fact, only become more visible as the diagnostic tools for studying it have improved.

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Conflict of Interest

The authors declare no conflicts of interest relevant to this work.

Author Contributions

Ines Nowicki conceived the review, synthesized the literature on judicial oversight and disability-rights critiques, and drafted the initial manuscript. Pieter Nowicki performed the literature synthesis on diagnostic uncertainty and neuroimaging and critically revised the manuscript. Wolfgang Rossi contributed the sections on surrogate decision-making and end-of-life care practice and provided final approval of the submitted version. All authors read and approved the final manuscript.

Ethics Statement

As a literature review synthesizing previously published, publicly available research and case law, this article did not involve new data collection from human participants and did not require institutional ethics committee approval.

Data Availability

No new data were generated or analyzed for this review. All sources discussed are cited in the reference list and are publicly available through their respective publishers.

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