



Birchley, G. (2013). Lynn Hagger and Simon Woods (eds.), A Good Death? Law and Ethics in Practice. *European Journal of Health Law*, 20, 528-531. DOI: 10.1163/15718093-12341292

Peer reviewed version

License (if available):  
Unspecified

Link to published version (if available):  
[10.1163/15718093-12341292](https://doi.org/10.1163/15718093-12341292)

[Link to publication record in Explore Bristol Research](#)  
PDF-document

This is the author accepted manuscript (AAM). The final published version (version of record) is available online via Brill at <http://booksandjournals.brillonline.com/content/journals/10.1163/15718093-12341292>.

## University of Bristol - Explore Bristol Research

### General rights

This document is made available in accordance with publisher policies. Please cite only the published version using the reference above. Full terms of use are available:  
<http://www.bristol.ac.uk/pure/about/ebr-terms.html>

**This is a prepublication draft, that was subject to minor edits before publication. If citing please use the following reference:**

Birchley, G. (2013) Book Reviews European Journal of Health Law 20 (2013) 513-539

Lynn Hagger and Simon Woods (eds.), *A Good Death? Law and Ethics in Practice* (Farnham: Ashgate Publishing, 2013), ISBN 978-1-40-942089-7 (hardback), £65, 194 pp.

This collection of essays by a multi-disciplinary group of authors offers the reader considerations of topics at the interface between life and death, with essays from a broad range of perspectives examining themes as diverse as the role of National Institute of Health and Clinical Excellence (NICE) in the distribution of health resources in terminal illness, and alternative policy models in the regulation of assisted suicide sitting side by side. The essays emphasise clinical, legal and ethical aspects of their chosen topic and the putative reader would be advised to have some grounding in one of these areas. This notwithstanding, for the novice reader there are noteworthy items. James Munby's survey of end of life decision making is an outstandingly clear and concise description of the topic that would be of great use to postgraduate students who are new to the workings of English law. Jeff Perring's narrative account of end-of-life decision-making in children's intensive care offers the reader insights into the complexities of sharing decisions with parents of a dying child that are necessary to fully appreciate the challenges of clinical practice in this area. In the main however, this collection would most appeal to those who already had some grasp of the topics it discusses; the essays are well written, and some choose novel issues and take insightful standpoints.

I found they strengthened my intimacy with topics where I had some knowledge but had formed little opinion, and therein I think the strengths of this collection lie.

Despite the title, few chapters explicitly seek to define what a good death is as such, although where such a definition can be glimpsed it is common to all authors that a good death is one that is both defined by the patient or their proxies, and de-medicalised, I will return to the potential contradictions of this standpoint in a moment. Simon Woods offers the firmest focus upon potential ambiguities of a good death. In an ambitious chapter he attempts to reconcile conceptions of the term that involve the active termination of life with the aspirations toward a de-medicalised death of the palliative care movement. Arising from the hospice movement, palliative care has both influenced, and been subject to the influence of, medical practice at large, and Woods suggests the effect of the palliative care movement's rigid distinction between acts and omissions may be incompatible with the natural death which the hospice movement originally sought, since it involves a normative standpoint which may impose a specific value of life upon the individual rather than allow it to be autonomously determined. Woods tries to bring unity to these approaches by contending that both the self-determined value of life utilised by the euthanasia movement and the sanctity of life approach of palliative care aim to improve the mental experience of dying by either curtailing or suppressing experience. Woods suggests that positive interventions to enhance these mental experiences with psychedelic or euphoric drugs may be a compromise between the two positions.

Besides this chapter, the book offers a broad range of topics connected to the theme. There is a strong legal focus in the essays of James Munby and Lyn Hagger. Munby's explores the law around competent requests for treatment, nontreatment

and assisted suicide. He concludes with an analysis of *Burke v. General Medical Council* [2005] EWCA Civ 1003, an important case on which he should be considered a particular authority, having as a High Court judge been overruled on his judgement by the Court of Appeal. Hagger, who features twice in this collection, considers the place of the law in resolving disputes about the treatment of children. In particular she challenges what she sees as an overly conservative approach to mature children's refusal of life saving treatment which significantly encumbers their right to autonomy. She argues for an approach that pays heed both to the Human Rights Act 1998 and the Mental Capacity Act 2005, believing there is scope within the HRA for a challenge to precedent. Current common law restricts mature minors' ability to refuse treatment that is considered to be in their best interests, and Hagger contends this may infringe on their Article 8 rights to privacy and family life, which broadly enshrines a right to moral freedom. Any residual concerns about the competence of mature minors may be readily remedied through the extension of the MCA's test of competence for over 16s, which includes expert assessment, to those below that age. Hagger also attempts to address the social context of the adolescent after death, considering the controls the law offers grieving families over their child's bodily material. Hagger features again in one of four essays with a policy focus. With Christopher Rehmann-Sutter, she considers potential reform to legal responses to assisted suicide in the UK. Currently, assisting suicide is illegal within our borders, yet relatives who assist a loved one in travelling abroad to commit suicide are likely to be tolerated. Accepting arguments that domestic law should be changed to allow assisted suicide, the authors examine debates in Swiss law, where a legal framework has been proposed to ensure that standards such as mandatory counselling on alternatives to suicide are followed. The chapter by Vincent Kirkbride

considers resource allocation in the NHS, particularly focusing on the rationing of costly treatments that may delay the end of life. Kirkbride considers the evolving position of NICE, including recently abandoned plans to downgrade its status in the Health and Social Care Act 2012, as well as the apparent undermining of NICE's funding decisions by the establishment of the (locally administered) Cancer Drug Fund which he suggests may presage inconsistencies in rationing decisions between different regions in a resurrection of the so-called 'postcode lottery'. Daniele Bryden's offering examines the medical definition of death, considering those patients who neither fulfil medical definitions of death, yet nevertheless are presumed to be beyond medical help. Her thorough explanation of medical diagnosis of death guides us through practical complications of cardiopulmonary death (it is largely diagnosed by the most junior staff, who have very minimal training) as well as identifying the somewhat pragmatic place of brain stem death, and its importance to the supply of organs for those in need of a transplant. Brain stem death has been argued to be a test of imminent death rather than death itself and Bryden reflects on this in her legal analysis. She argues that in brain stem death, along with persistent vegetative state and elective ventilation of patients for organ harvesting, a liminal category of peri-death has been created by medicine. Statutory law, in choosing to overlook this category, fails to provide either clear boundaries for practitioners or reassurance for grieving families. John Erik Troyer's essay considers recent attempts by the pro-life movement in the United States to introduce amendments to the constitution defining foetuses as persons. The intention of such amendments is the conferring of full constitutional rights and protections to the early cellular human life arising from the first meeting of sperm and ova. While setting out the origins and beliefs of the movement, Troyer also considers the implications upon the dead and dying

that such amendments would entail should they come into law, given that this definition of life implicitly denies currently accepted forms of death.

As previously noted, the prevailing view within these chapters is that a good death is both autonomously defined and de-medicalised, in other words, that we ought to treat only so long as such treatment is curative. Yet there are tensions in this tying of autonomy to one particular view of a good death as some may autonomously wish to be treated maximally to the point of death or beyond.

A good death depends upon our conception of good: When the poet Dylan Thomas imprecated his dying father “Curse, bless, me now with your fierce tears, I pray. / Do not go gentle into that good night. / Rage, rage against the dying of the light.” He expressed a view of the good death that was quite at odds with the view of Socrates, described by Plato in *Phaedo*, that: “I should only make myself ridiculous in my own eyes if I clung to life and spared it, when there is no more profit in it.” In presenting a good death merely as Socratic rationality, we overlook a morally significant opinion that we must “rage against the dying of the light” with all the force that medicine can muster, no matter how irrational our intent. On a rational level, these essays do engage with that latter perception: Simon Woods’ essay on reconciling of palliative care and euthanasia obliquely addresses the divide. Troyer more readily engages with it, and it is through this type of exploration of the consequences of a moral position that we more readily can disarm those that are irrational. This is also true for Kirkbride’s exploration of health rationing and Hagger and Rehmann-Sutter’s consideration of arguments for and against legalising assisted suicide. But perhaps the defect in such rational engagement is that many common, human, responses defy rationality.

On this count, the final two essays, both about the care of infants at the end of life, play an important role in balancing the collection. Jeff Perring offers a case

study-based, narrative account of end-of-life decision-making practice. He carefully describes the delicate path which a clinician must traverse in order to pay due heed to the intimate bond between the interests of children and parents. On such a path, the clinician leads and encourages the parent, mapping future points where challenging decisions must be taken, and patiently waiting for parental hopes and aspirations to coincide with grim realities. The final chapter is the obverse of Perring's clinical account: Sabine Vanacker offers a moving account of the life and death of her infant daughter, Isabel, who died as a result of a terminal genetic illness. The account travels from the diagnosis of the illness, the paradox of witnessing Isabel's growth and continuing development even amid a wider degeneration of her body and person as the disease progressed (a powerful example of the sort of unique knowledge a parent may have of their child), the careful and gradual reorientation of her care toward comfort and away from the preservation of life at all costs, her death and the continuing part she plays within her family's life seven years after the event. Vanacker's account reminds us both of what we can and cannot say about the death of a loved one, and I was struck by the profound and mystical effects of bereavement that are no less real for its lack of explanation in rational terms. We must somehow address the irrational, profound experience in a way that is coherent and of practical benefit, and the narrative method both Vanacker and Perring employ is appealing from this point of view.

That the essays in this collection are guided by a common perception of a good death lends them some unity, but too little to prevent them standing and falling on their own merits. Yet on this count each is clear, thought-provoking and engaging, and this is therefore a collection that will have wide appeal.

Giles Birchley

Wellcome Trust Biomedical Ethics Research Fellow;

Doctoral student, Centre for Ethics in Medicine, University of Bristol, UK.