

## Preface

The cases of Charlie Gard and Alfie Evans were among the most high-profile doctors-parents disputes in England and Wales in recent times. They were contested throughout the entire hierarchy of the domestic court system, and beyond, to the European Court of Human Rights. Appeal after appeal failed to reverse the respective court of first instance's declarations that the continuation of ventilatory support and life-sustaining treatment were not in the infants' best interests. Still, what is particularly noteworthy about the two cases is not just the debates that took place in the courtrooms. Few medical law cases have attracted as much global attention and even interventions from well-meaning individuals and institutions unconnected to the two infants.

This book explores the issues and challenges posed by these and similar cases, both inside and outside the courtroom. It also examines how other jurisdictions would deal with comparable situations. The book consists of 17 chapters, written by scholars with expertise in law, medicine, medical ethics, theology, health policy and management, English literature, nursing, and history, from the UK, Australia, Canada, the Czech Republic, France, Germany, India, Spain, Turkey and the USA.

The first chapter sets the context for the book by documenting the chronology of medical events relating to the two infants, as accompanied by the legal arguments which were fielded and debated during their protracted courtroom battles. The subsequent 16 chapters are organised into 2 Parts. Part I takes an interdisciplinary look at the wide range of issues raised in the two cases, as well as medical futility in paediatrics generally. Part II sheds light on how these situations are likely to be managed in other jurisdictions.

Part I begins with an important reminder from Jo Samanta that intractable disputes between doctors and parents relating to seriously ill infants are neither new, nor unusual. Her chapter examines the evolution of the best interests test when used in this area, and considers the possible role of mediation as a vehicle for alternative dispute resolution. William Seagrim's chapter defends the continued usage of the best interests test which, as a yardstick in paediatric cases, has been labelled the "gold standard." He points out that although some commentators have suggested that it insufficiently protects parents from state intervention and have called instead for an enabling "significant harm" threshold, such submissions are devoid of any legal basis. The following chapter by Sarah Sargent offers a contrasting viewpoint. In her discussion of *Charlie's Law*, she explores the significance and benefits of clearly establishing the "significant harm" threshold to ensure more

protection for parental wishes and to reduce needless interference from healthcare professionals and the courts.

Looking next at the role of the media in making public the difficult nature of medical futility cases, Kim McGuire discusses interpretations of the media role, as both “positive” and “negative.” Whilst for the families, media reporting widened access to avenues of support; for healthcare professionals, it brought abuse and declining trust. This chapter concludes by considering mediation as a means for expressing and resolving conflicting viewpoints outside the media gaze. Richard Law then identifies the extent to which resource-intensive medical treatments place significant financial burdens on healthcare systems especially in the provision of life-sustaining care to critically unwell patients. His chapter analyses the clinical and legal implications of limited resources and the nature of the impact that medical crowdfunding exerts on resource allocation. The ensuing chapter by Alejandra Boto focuses on the reported conferral of Italian citizenship to Alfie Evans despite the apparent absence of an Italian lineage. Approaching the issue from a public law perspective, she discusses Italy’s legal provisions relating to the conferral of citizenship to foreign nationals and provides a comparative analysis with Spain.

Brendan McCarthy’s chapter highlights that the Church of England views medical ethics through the prism of four cascading principles: affirmation of life; care of the vulnerable; creation of a caring and cohesive society; and respect for individuals. This framework provides a principled, consistent guide for all areas of care including when determining the best interests of children in the context of potentially futile medical intervention. Mahmood Chandia and Abdulla al-Shami then look at the debate from an Islamic legal (*fiqh*) perspective by addressing two questions: what is the scope of parental rights and responsibilities in Islam; and how would Islamic *fiqh* guide parental thinking in such situations? Part I ends with Lisa Cherkassky’s chapter which examines whether parents have the legal right to take their gravely ill hospitalised children home, to die, and whether this final wish should be afforded more weight in the future.

Part II begins with a chapter from Roslyn Jones which considers the legislative provisions and case law on comparable matters in Australia and analysing those cases in terms of issues of quality of life, professional obligations, parental versus state control, and the use or misuse of media and social media. Next, Helena Krejčíková highlights that in the absence of any explicit legislative recognition of medical futility in the Czech Republic, clinical practice relies predominantly on a vague statutory definition of proper care and two non-binding guidelines aimed, however, at adult patients. Her chapter introduces readers to the Czech legal framework and clinical practice, including a new document prepared by the Paediatric Palliative Care Working

Group on providing life-sustaining care, which would apply in cases similar to those of Gard and Evans. French Law's response to medical futility relating to minor patients is then examined by Stephanie Rohlfing-Dijoux. Her chapter assesses how the country's end-of-life legislation can be conciliated with its child protection law and legislative provisions relating to minors in family law. Peter Elsner's chapter, which focuses on Germany, appraises how decisions regarding the continuation or termination of medical support measures in end-of-life situation involving child patients are balanced against the right to life enshrined in the German Constitution.

In the next chapter, Abhay Vaidya and Sourabhi Sahakari review the Indian healthcare and legal systems. By illustrating how different these are from the NHS and the standpoints taken by English Law, they seek to show that the Gard and Evans cases are unique products of their environment. Banu Buruk and Berna Arda explore in their chapter the different, and at times contrasting, set of challenges faced by doctors and parents in a communitarian society like Turkey, and describe how the best interests of child patients are usually determined therein. The final chapter in Part II by Vincent Maher compares Gard and Evans with the Jahi McMath case in the USA. It asserts that medical diagnoses pertaining to medical futility and treatment should take precedence over the unrealistic preferences of families fuelled by the dramatic pressures of social media.

The book hopes to enrich the ongoing debates surrounding medical futility in paediatrics, and to encourage parents and healthcare professionals faced with this dilemma in the future to consider a wider range of options.

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