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Puteri Nemie Jahn Kassim

Ethics and the Law on End-of-Life Decisions in Malaysia

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ISBN 978-981-92-3624-4 ISBN 978-981-92-3625-1 (eBook)
<https://doi.org/10.1007/978-981-92-3625-1>

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To my most beloved late parents, Dr. Rohani Ahmad and Dr. Alias Kamis, whose unconditional love and unwavering faith in me continue to be a beacon throughout my life journey. Through them, I have come to understand the true meaning of the words of Prophet Muhammad (peace and blessings be upon him):

“The best of people are those who are most beneficial to others”.

*Until we meet again
in the gardens of eternal peace,
where hearts are at ease
and only blessings remain.*

Foreword

It is my honour and privilege to be invited to pen the foreword for this book on *Ethics and the Law on End-of-Life Decisions in Malaysia*.

Advancements in medicine have successfully extended our life expectancy rates and significantly reduced illness-related morbidity. Nevertheless, the elixir of immortality has remained elusive. The Latin phrase *memento mori* reminds us of our mortality and the inevitability of death. While many may not be comfortable to initiate or be involved in a discussion on this topic, as living beings, each one of us will need to embrace death as a certainty.

In the clinical setting, end-of-life practices continue to evolve based not only on scientific evidence, but also on socio-religious-cultural factors. However, advancements in this field do not necessarily just mean “more treatment”. It is also addressed by how we can afford patients “more comfort”, “more dignity” and “more meaning” to their suffering. Decisions that are made about our end-of-life choices often highlight the complexities in the perennial debate about weighing the quantity of life versus the quality of life, and the position of the sanctity of life. As humans, we are social beings, and the rationale for these decisions that are made at such a critical point in our lives often uncovers philosophical roots that are manifested and result in practical realities that not only affect us individually, but also bear an impact on those who surround us—our families, friends, community and society.

In this book, readers are brought by the authors on a journey to unravel the complexities that surround end-of-life decision-making in Malaysia. It begins with a description of the conceptual and contextual foundations of end-of-life decisions in Malaysia. The authors then consider the ethical dimensions and legal issues related to end-of-life decision-making before shifting the focus to an examination of the current regulatory frameworks on end-of-life decisions in Malaysia. Following this, they then set the foundation for moving towards a coherent ethico-legal framework that is so needed in Malaysia before providing tangible proposals for how the future direction for holistic regulatory reforms in this area should entail. These include the avoidance of misleading terminology such as “passive euthanasia”, clearer legal protection for doctors, the promotion of advance decision-making tools such as

advance care planning, the need for mental capacity legislation, and the importance of cultural competence as well as profession and ethical conduct.

The discussions, debates and analysis in this book are timely for two reasons. Firstly, the World Bank projects that Malaysia will move from being an upper-middle income developing country into a high-income developed country between 2028 and 2030. Secondly, Malaysia is currently an ageing society and is projected to transition into an “aged nation” by 2045. As we stand at the threshold of these two significant transitions, issues surrounding end-of-life decisions need to be examined and contextualised to our local setting. This decolonising process requires careful consideration of the societal values and cultural norms to develop suitable and meaningful ethico-legal frameworks that guide the development of medical practice in this area in Malaysia.

As a clinical ethicist, I am able to attest to the fact that some of the most complex and diverse ethical dilemmas related to medicine are often found in end-of-life decision-making. In manoeuvring through them, I am often reminded of this quote by Edmund Pellegrino, a key pioneer in clinical bioethics and the philosophy of medicine, who said that medicine is “the most humane of sciences, the most empiric of arts, and the most scientific of humanities”. As we engage with the contents of this book, and the dilemmas and debates on end-of-life decisions in Malaysia, I urge you to consider how we are able to reconcile the science of medical advancements at the end of life with the art of dying well.

It is my hope that this book will prove to be a seminal text on end-of-life decision-making in Malaysia, and I am sure that will not only benefit scholars of medical law and bioethics, medical and legal practitioners, policymakers and students, but everyone who engages with its content—for all of us will be called upon to make such decisions at some points in our lives—be it for ourselves or for others.

Lastly, allow me to conclude with one last consideration on this topic, which is illustrated with a quote from Dame Cicely Saunders who pioneered the modern hospice movement, that “how people die remains in the memory of those who live on”. Congratulations to the authors on the production of this scholarly work, and may it enhance our understanding, create even more awareness, and guide us in making good decisions about the end of life.

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23 May 2026

Mark Kiak Min Tan

Preface

End-of-life care is an area of medical practice where questions of law, ethics, religion, culture and clinical judgement often meet in difficult and sensitive circumstances. Advances in modern medicine have made it possible to prolong life in ways that were once not medically possible. While this has brought considerable benefit to patients and families, it has also raised difficult questions on when treatment should be continued, withheld or withdrawn, how suffering should be relieved, and how decisions ought to be made when a patient is approaching the end of life.

These questions are especially important because they are rarely abstract. They arise at moments of vulnerability, when patients may be seriously ill, families may be emotionally distressed, and doctors may be required to make decisions under considerable professional and moral pressure. In such circumstances, the absence of clear legal standards may create uncertainty for all parties involved. It may leave doctors unsure of the extent of their legal protection, patients uncertain as to whether their wishes will be respected, and families without sufficient guidance in making or participating in difficult decisions.

This book is written against that background. Its central concern is the need for a coherent ethico-legal framework on end-of-life decisions in Malaysia. Existing ethical codes, professional guidelines, palliative care standards and recent developments on advance care planning and consent have contributed meaningfully to the development of medical practice in this area. Nevertheless, important issues are yet to be addressed with sufficient legal clarity, particularly in relation to withholding and withdrawal of life-sustaining treatment, palliative measures that may foreseeably hasten death, advance decisions, surrogate decision-making, mental capacity and the legal protection of doctors who act in good faith and in accordance with proper professional standards.

The need for clearer guidance must also be understood within Malaysia's own social and normative setting. End-of-life decisions in Malaysia cannot be separated from religious belief, cultural values, family involvement and the realities of medical practice. For that reason, any proposed framework should not proceed on the basis of adopting foreign models without due regard to local circumstances. While the common law experience of jurisdictions such as the United Kingdom and

Australia offers useful points of reference, the development of Malaysian standards must remain attentive to local legal, professional and social circumstances.

At the same time, sensitivity to local context should not result in the continued absence of clear standards. End-of-life decisions concern matters of profound importance: the dignity of the patient, the relief of suffering, the role of the family, the professional duties of doctors and the limits of medical intervention. A more coherent framework would not remove the emotional difficulty of such decisions, but it may provide a firmer basis upon which they can be made with greater clarity, legitimacy and compassion.

This book therefore seeks to examine end-of-life decisions in Malaysia through an integrated ethico-legal lens. It considers the ethical principles that inform medical decision-making, including the manner in which these principles are reflected in Malaysian professional ethical guidance. It then examines common law principles developed in comparable jurisdictions, not as models to be adopted without qualification, but as sources of reasoning that may assist in addressing areas where Malaysian law remains unclear. The discussion thereafter turns to the adequacy of the current Malaysian statutory and regulatory position. Its purpose is not to reduce end-of-life care to a question of legal compliance, but to consider how law may better support ethical, compassionate and professionally responsible medical practice.

The book is intended for legal scholars, medical law and bioethics researchers, healthcare professionals, policymakers, postgraduate students and readers with an interest in the development of palliative and end-of-life care in Malaysia. It is hoped that the discussion will contribute to a more coherent and locally responsive understanding of how patients, families and doctors may be better supported in navigating decisions at the end of life.

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Acknowledgements All Praise to Allah, the Bestower of Faith, the Most Compassionate and the Most Beneficent, for it is only by His Will and His Guidance that this book has been made possible.

This work would not have come to completion without the support, guidance and kindness of many individuals and institutions. We wish to express our deepest appreciation to the Springer editorial team, especially our editor, Alexandra Campbell, whose counsel, patience, encouragement and invaluable support have accompanied us throughout the publication process. We are truly grateful for her confidence in this project and for the care with which she has guided it from its early stages to completion.

We would also like to convey our sincere gratitude to the reviewers of this book for their thoughtful reading, valuable insights and constructive feedback. Their comments have helped us reflect more carefully on our arguments and have contributed meaningfully to the refinement of this book.

A special note of appreciation is extended to Dr. Mark Tan for graciously writing the foreword to this book. His willingness to lend his voice to this work is indeed an honour, particularly given his long-standing engagement with the field and his familiarity with our work.

Profound thanks are also due to our colleagues, whose words of encouragement and goodwill have meant a great deal to us throughout the writing process. We are equally grateful to our respective institutions, Universiti Sains Islam Malaysia and International Islamic University Malaysia, for providing the institutional and academic support that enabled us to undertake and complete this project.

This book has been shaped by an academic relationship that we both value deeply. What began as a supervisor–student relationship has grown into a collegial and scholarly collaboration founded on mutual respect, trust and intellectual openness. Over time, the mentoring relationship between teacher and student has also grown into a close friendship, held with gratitude and affection. We are grateful for the opportunity to have brought this work to completion together, and for the many conversations, reflections and shared commitments that have enriched the process.

Although this book is a collaboration, we wish to record our personal appreciation to those closest to us, whose devotion and quiet sacrifices have carried us through this undertaking.

Fadhlina would like to express her heartfelt gratitude to her husband, Mohd Fairuz, her only sibling, Ahmad Fadhil and his wife, Helwa Husna, as well as her other family members and relatives, for their patience, prayers, advice, understanding and unwavering support throughout the writing process. Their love, encouragement and faith have been a constant source of strength, especially during the most demanding moments of this journey.

Puteri Nemie wishes to express her deepest appreciation to her beloved family, whose love, prayers and quiet encouragement have accompanied her throughout the

preparation of this book. Their understanding and steadfast support have brought comfort and remained an important source of reassurance throughout this endeavour.

Finally, we wish to thank everyone who has contributed to this book, whether through intellectual guidance, professional support, personal encouragement or prayers. This work has come to fruition not only through our own efforts, but also through the generosity, kindness and support of many others. Any errors or omissions that remain are, of course, entirely our own.

Competing Interests The authors have no competing interests to declare that are relevant to the content of this manuscript.

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