A POSITION PAPER
ON
ADVANCE MEDICAL DIRECTIVES: ETHICAL SAFEGUARDS

ADVANCED MEDICAL DIRECTIVES ACT, 2026

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Contents

Executive Summary

This position paper has been prepared by an interdisciplinary group of academics from the University of Malta, bringing together expertise in medicine, ethics, theology, philosophy, law, and jurisprudence, in collaboration with senior clinical staff at Mater Dei Hospital, in response to the proposed Advanced Medical Directives Act (2026). The proposed legislation aims to establish a legal framework governing the drafting, registration, recognition, and implementation of advance medical directives. The authors welcome this initiative as both timely and necessary, particularly in safeguarding patient dignity at the end of life, supporting families faced with difficult decisions, and providing guidance and legal protection to healthcare professionals. Nevertheless, the paper identifies several ethical considerations that must be addressed to ensure that the legislation achieves its intended purpose while protecting vulnerable individuals and maintaining sound clinical judgement.

A central concern of the position paper is the need for a prudent interpretation of advance medical directives. While legal clarity is essential, decisions at the end of life cannot be reduced to a purely legalistic application of written instructions. Rather, advance directives must be interpreted within a broader ethical framework that includes prudence, proportionality of treatment, and respect for human dignity. The paper distinguishes between two commonly recognised forms of advance medical directives: the living will and the durable power of attorney for healthcare. It notes that the Bill provides for living wills but omits provisions for healthcare proxies, which are often considered more flexible and effective in ensuring that patient wishes are respected in complex clinical situations.

Particular attention is given to artificial nutrition and hydration (ANH), which the Bill treats as life-sustaining interventions. The paper identifies three broad clinical scenarios. First, temporary ANH in reversible conditions generally falls outside the scope of advance refusals. Second, long-term ANH in chronic illness may shift over time from supportive care to life-prolonging treatment, requiring prudent reassessment in light of evolving circumstances. Third, in the final stages of dying, ANH may become burdensome and ethically permissible to be withdrawn, particularly where its continuation increases discomfort or prolongs suffering. In these cases, the focus of care shifts from sustaining physiological functions to providing comfort, alleviating suffering, and supporting families.

Throughout the paper, emphasis is placed on maintaining the distinction between proportionate and disproportionate treatment, and between allowing natural death and euthanasia. Advance medical directives should guide clinical decision-making, preferably, in the context of advanced care planning. Additionally, the paper stresses the need to safeguard vulnerable individuals, particularly elderly persons, from coercion or subtle pressure when drafting advance directives.

This paper also acknowledges that, despite the presence of a clear advance directive, the patient's actual circumstances may not fully align with those anticipated in the directive. For this reason, it proposes the inclusion of a durable power of attorney alongside the advance medical directive.

The paper concludes with several recommendations, including: promoting advance care planning rather than relying solely on written directives; introducing a durable power of attorney for healthcare; establishing clinical ethics consultation services; strengthening palliative care; introducing a conscience clause; reviewing DNR practices; clarifying mental capacity assessment procedures; ensuring safeguards against coercion; providing clinical guidance on ANH; and allowing individuals to express ethical or religious values to guide interpretation of directives.

Ultimately, the paper affirms that advance medical directives can serve as valuable instruments for compassionate and ethically responsible end-of-life care, provided they are embedded within a robust ethical framework that prioritises dignity, prudence, and solidarity.

Position Paper

Introduction

1. The rapid advances in medical technologies, coupled with a widespread cultural fear of death and the increasing legal pressures surrounding healthcare practice, have made the introduction of advance medical directives both timely and viable. Advance medical directives can contribute towards the safeguarding of the dignity of patients, assist relatives when difficult medical decisions must be taken, and provide guidance and legal protection to healthcare professionals who might otherwise resort to defensive medicine.[1] Advance medical directives, however, are not a panacea and cannot resolve every ethical dilemma encountered at the end of life. Their ethical value depends largely on the robustness of the safeguards accompanying them and on the clarity of the legal and ethical framework within which they operate. Several countries have already introduced advance medical directives within their healthcare systems, recognising their potential to respect patient autonomy while ensuring responsible clinical decision-making.[2]

2. This position paper was initially prompted by a press statement issued by the Parliamentary Secretariat for Equality and Reforms on 2 March 2026 announcing that a White Paper would be tabled establishing rules governing the drafting and implementation of Advance Medical Directives in Malta. Since that announcement, the bill for an Advanced Medical Directives Act, 2026 has been published, proposing a legal framework regulating the drafting, registration, recognition, and implementation of such directives. The academics contributing to this paper, hailing from various interdisciplinary fields, to an extent welcome this legislative development, which could represent an important step towards safeguarding the dignity of persons in an evolving technocratic medical environment.[3]

3. The object and reason of the proposed legislation, as described in the Bill entitled Advanced Medical Directives Act, 2026, is "to establish a clear legal framework regulating advance refusals of medical treatment and provide legal protection and guidance to medical practitioners implementing such directives". The Bill states that the Act would provide legal recognition to advance refusals of specified medical treatments made by competent individuals and introduces a number of procedural safeguards governing their preparation, authentication, and implementation. In particular, it requires consultation with a medical practitioner, certification of mental capacity, authentication before a notary, and

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[1] Emmanuel Agius, Carlo Calleja, Raymond Zammit et al., "Position Paper on the Public Consultation on 'Assisted Voluntary Euthanasia'," Academics, University of Malta, 2025, para. 7.

[2] Denard Veshi and Gerald Neitzke, "Advance Directives in Some Western European Countries: A Legal and Ethical Comparison between Spain, France, England, and Germany," European Journal of Health Law 22, no. 4 (2015): 321–345.

[3] Department of Information, "Stqarrija mis-Segretarjat Parlamentari għall-Ugwaljanza u r-Riformi Liġi Ġdida Ser Tagħti Drittijiet Ġodda dwar il-Kura Medika," Press Release PR260346, 2 March 2026. Available online at https://www.gov.mt/en/Government/DOI/Press%20Releases/Pages/2026/03/02/PR260346.aspx. The drafting of the White Paper was endorsed by the Prime Minister on 2 Mach 2026 as Motion no. 451. For further updates see https://parlament.mt/14th-leg/motions/motion-no-451-advanced-medical-directives/.

registration within the relevant public and medical record systems. These measures seek to ensure both the authenticity of the patient's wishes and the legal protection of healthcare professionals who act in accordance with valid directives.

4. Since every legal framework on any matter implies an ethical dimension, this position paper will focus on some of the ethical issues implied in the particular legal framework that is being proposed. Some of those issues relate to the directives that the individual may want to make regarding his or her end-of-life medical treatment. Other ethical issues relate to the legal provisions governing the implementation of advance medical directives, especially by medical practitioners. In both cases, the rights assigned to the individual to make legally enforceable advance medical directives, and the obligations of medical practitioners to implement those directives should not be regarded simply as a matter of following the letter of the law. Living and acting in a truly human way involves something more than mere compliance with the law. Whatever the law requires needs to be interpreted and applied with reference to basic ethical principles. Besides, a decision on any important and serious matter, such as advance medical directives, is ethically good if it is based on a prudential judgement, that is, a judgement about what the concrete situation actually requires. Such a judgement should not be based solely on what the law requires. Rather, it should seek to discern what is truly right, while still giving due consideration to the law. In other words, the situation must be interpreted from both a legal and an ethical perspective.

5. The ethical framework underpinning this position paper draws upon principles traditionally employed in bioethics, including respect for autonomy, human dignity, and free and informed consent, as well as the principle of proportionality in medical treatment, the distinction between ordinary and extraordinary means of care, and the ethical evaluation of treatments that may be considered burdensome or medically futile. It is also situated within a broader moral horizon that recognises social principles such as solidarity, subsidiarity, and the common good, as well as the ethics of care and the civil virtues required to sustain compassionate healthcare systems.

6. The introduction of the Advanced Medical Directives Act Bill reflects the outcome of consultations with stakeholders in the healthcare sector. However, as with any legislative initiative touching upon sensitive issues of life, death, and medical decision-making, ongoing dialogue remains essential. In particular, the perspectives of patients, carers, vulnerable populations, and healthcare professionals involved in end-of-life care must continue to inform the development of the regulatory framework and its practical implementation, complemented by the expertise of specialists in healthcare law. This position paper, written by academics from different fields, seeks to contribute to the ongoing ethical reflection accompanying the legislative process by examining how the provisions of the Bill interact with the ethical principles governing end-of-life care.

7. Before addressing its central questions, it is necessary to clarify the key terms employed by the Bill and to situate the legislation within the broader landscape of advance care planning instruments. Thereafter, this paper will consider, first,

the extent to which advance medical directives can serve as an adequate legal instrument enabling individuals to participate in decisions regarding their end-of-life care, given that they represent only one possible approach to such care; secondly, the ethical issues that arise in their formulation and implementation; thirdly, specific ethical concerns; and finally, it will offer a number of recommendations.

Part I: The Scope of Advance Medical Directives

While the Bill refers only to Advance Medical Directives, the press release used this interchangeably with the living will. Therefore, it is helpful to distinguish between the two.

8. *Advance Medical Directive*: This is a legal document through which, traditionally, a competent individual expresses preferences regarding medical treatment in the event that he or she later becomes incapable of making or communicating healthcare decisions. The Bill defines an advance medical directive more specifically as a prior decision made by a competent person refusing specified medical treatment in defined circumstances when that person lacks the capacity to provide consent. Advance medical directives generally take two principal forms. When the document specifies the individual's preferred treatment options in particular medical circumstances, it is commonly referred to as a 'living will'. When it designates another individual to make healthcare decisions on the patient's behalf, it is commonly referred to as 'a durable power of attorney for healthcare'.

9. *Living Will*: This is a specific form of advance medical directive through which an individual expresses preferences regarding medical treatments that he or she would wish to accept or refuse in circumstances where decision-making capacity has been lost. Such directives typically concern medical interventions that may prolong life in situations of serious illness, terminal conditions, or irreversible unconsciousness. The purpose of a living will is to give binding direction to healthcare professionals and family members in making decisions that respect the patient's previously expressed wishes, values, and beliefs.

10. The general provisions of the Bill delineate the scope of the proposed legislation, restricting it to advance medical directives. Of course, this does not mean that an individual may not wish to pursue other ways in determining the kind of care he or she may want to get in certain medical circumstances, when lacking the capacity to decide for him/herself. In fact, the Bill itself refers to advance medical planning (clause 4 (2)). Unlike the other key terms, however, this one is not defined. It is actually restricted to the assistance which the medical practitioner is required to give to the individual making the directive. Advance medical directives are certainly important but advance care planning covers quite a broad

area of health care and involves more than communication between the patient and a medical practitioner.[4]

11. Advanced Care Planning (ACP) refers to a voluntary process of communication and reflection whereby an individual discusses his or her values, beliefs, goals and preferences regarding future medical treatment and end-of-life care, together with a medical practitioner and, if possible and helpful, with loved ones, in anticipation of a time when he or she may lose decision-making capacity. It is a broader relational process that may lead to a proper drafting of advance medical directives. ACPs are preferences and wishes and not legally binding, but an Advance Medical Directive (AMD) is a specific legal document. Whilst ACPs may specify within them any AMDs that the patient has, such as refusal of certain treatments (but not vice versa), an AMD does not hold ACPs within it. To illustrate, an ACP may contain a wish to die at home; if this for some reason could not be upheld, it will not lead to any legal responsibility or issues.

12. One may acknowledge that, for the purpose of legislation, advance medical directives are often used to define and limit the scope of regulation. However, when addressing a matter as significant as end-of-life healthcare, it is important not to create the impression that such directives constitute the only, or the most adequate, means of regulation. Another legal instrument that may serve a very useful role in the case of end-of-life treatment is the appointment of a durable power of attorney for healthcare. The Bill does not provide for this mechanism. This omission is significant and will be addressed later in the recommendations of this paper. A healthcare proxy is arguably a more flexible and ethically robust instrument than a written directive since a trusted proxy can interpret the patient's wishes in light of unforeseen medical circumstances and engage collaboratively with healthcare professionals in ways that a static document cannot anticipate.

4 Geriatric Medicine Society of Malta, Advance Care Planning? A Guide for Clinicians, https://gmsmalta.com/wp-content/uploads/2024/04/Advance-Care-Planning.pdf

Part II: Ethical Considerations

13. The right to make advance medical directives enables one to participate, amongst other things, in his or her end-of-life treatment in the eventuality that one, for instance, has impaired decision-making capacity in the future. In this respect, its purpose is ethically sound, because it is reasonable that individuals participate in determining the healthcare they may wish to receive up to the end of their life. Rightly enough, the proposed legislation sets a number of conditions for advance medical directives to be legally valid. The individual will not be given a *carte blanche* to make whatever advance directives one wishes. In fact, clause 3(3) provides that any stipulation contained in a directive requiring an omission, instruction or practice that is contrary to law shall be null and void. This provision constitutes an important safeguard, the ethical implications of which will be examined in the paragraphs that follow.

14. Hence there are both legal and medical parameters that must be observed in the making and implementation of advance medical directives. Schedule 1, annexed to the Bill, includes a model form for the legal recognition of the declaration made by the individual making advance medical directives (referred to as the 'appearer') as well as for the required medical and notarial certification. What the individual is legally required to declare, and what the medical practitioner and the notary have to certify, indicate the legal responsibilities that each party respectively assumes. As already noted, legal requirements, including those regulating advance medical directives, take on a broader dimension when considered from an ethical perspective.

15. The Bill refers to Schedule 1 as a *model form* which "may be used for the purposes of assisting appearers and medical practitioners in the drawing up of a directive" (Art. 4(5). This implies that any declaration regarding advance medical directive made by a competent individual will have legal effect as long as it is signed by a medical practitioner and certified by a notary. The risk with such forms, particularly when their use becomes routine, is that the process risks being reduced to a mere box-ticking exercise. While this may satisfy the relevant legal requirements, ethically speaking, a serious matter such as an advance medical directive calls for a more substantive process of reflection and consultation.

16. From an ethical standpoint, the principle established by clause 3(3) must be interpreted in light of the distinction between ordinary and extraordinary means of prolonging life. One is morally justified in excluding extraordinary means of prolonging life, that is, medical interventions that the patient considers disproportionate, excessively burdensome, or no longer beneficial. It is important to maintain this distinction because it is what separates allowing natural death from euthanasia. However, serious questions arise as to whether this mechanism actually provides an ethically adequate response to the complexities often involved in concrete medical situations. In urgent clinical circumstances, even the ten-day judicial timeline prescribed by clause 8(5) may be clinically insufficient. This paper therefore recommends establishing a clinical ethics consultation mechanism as a first-resort alternative to judicial proceedings, reserving court referral for cases where clinical and ethical dialogue has failed to produce agreement.

17. The question of judicial adequacy is not merely rhetorical. It points to a deeper tension that runs throughout the legislative framework under consideration, namely, the tension between legal adequacy and ethical integrity. While the law can establish formal requirements, provide model forms, and designate judicial mechanisms for resolving disputes, it cannot, by its very nature, fully capture the moral complexity inherent in decisions. Legal compliance does not automatically translate into ethical integrity. A directive that satisfies every procedural requirement may nonetheless fail to reflect the genuine, informed, and morally considered wishes of the individual who made it. Conversely, a clinical team that implements a directive strictly according to its letter may still act in a manner that is ethically questionable if the spirit and context of the patient's wishes are not adequately understood and respected. It is precisely this gap between legal form and ethical substance that warrants careful and sustained reflection.

18. The Bill attempts to address some of these concerns through specific safeguards. These include the requirement that directives be drafted with the assistance of a medical practitioner, authenticated by a notary, securely recorded within medical records, and implemented only when clearly applicable to the clinical circumstances described by the patient. Nevertheless, ethical reflection remains necessary to ensure that the legal provisions are interpreted in a manner consistent with responsible medical practice. Moreover, medical decision-making often occurs within highly sensitive clinical contexts where moral, cultural, and religious perspectives may significantly shape attitudes toward treatment. The following section, therefore, examines the most significant ethical issues that are likely to arise in the context of advance medical directives. Particular attention is given to questions surrounding artificial nutrition and hydration, the proper understanding of patient autonomy, the distinction between allowing natural death and euthanasia, the protection of vulnerable persons, and the role of family members and surrogate decision-makers in interpreting the patient's wishes.

19. A note on a further provision of the Bill deserves attention before turning to those specific issues. Clause 7(2)(b) provides that a directive shall not apply where "the treatment or circumstances do not correspond to those specified in the directive." This requirement is an important safeguard against the misapplication of directives, but it also raises a concern that the paper addresses at paragraph 22 below: the risk that a strict reading of this provision may render directives ineffective precisely in the situations where they are most needed, given that end-of-life circumstances are frequently more complex and unpredictable than any written document can fully anticipate.

Part III: Specific Ethical Issues

20. *Artificial Nutrition and Hydration*: One of the most sensitive and frequently debated issues in discussions concerning end-of-life decision-making is the withholding or withdrawal of artificial nutrition and hydration (ANH). The Bill explicitly recognises ANH as forms of life-sustaining treatment that may be refused within an advance medical directive. Notably, artificial nutrition and artificial hydration are listed separately in Schedule 1, meaning that one could opt to refuse artificial nutrition but not artificial hydration, or vice versa. This separation reflects a clinically and ethically significant choice that deserves careful analysis. It is not always the case that the withdrawal of artificial nutrition without artificial hydration serves the patient's comfort; in some clinical scenarios such a separation may prolong rather than ease the dying process, raising questions about proportionality and the coherence of the directive as a whole. This paper recommends that implementing guidelines address this issue explicitly, assisting both medical practitioners and appearers in understanding the clinical implications of treating these two interventions independently.

21. Ethical concerns arise primarily from the perception that discontinuing ANH may constitute a form of euthanasia or may conflict with deeply held moral or religious convictions that continue to influence healthcare decision-making even within secular healthcare systems.[5] At the same time, contemporary medical ethics recognises that not all medical interventions are ethically obligatory in every circumstance. In practice, three broad clinical scenarios may be distinguished, each presenting distinct ethical considerations:

    a. *Temporary artificial nutrition and hydration*: In certain clinical circumstances, the administration of artificial nutrition, for example, through a nasogastric tube (NG tube) or percutaneous endoscopic gastrostomy (PEG), the latter typically used when ANH is anticipated to be required long-term, may nonetheless be intended as a temporary measure. This may occur, for instance, in patients recovering from gastrointestinal surgery, stroke, or other acute conditions that temporarily impair swallowing. In such circumstances, artificial nutrition may be appropriately understood as a supportive intervention with clear therapeutic intent of supporting recovery, provided it continues to offer benefit without disproportionate burden.[6] Consequently, its withdrawal would not ordinarily be ethically justified until the patient regains sufficient capacity to safely resume oral nutrition.

    b. *Long-term artificial nutrition and hydration in chronic illness:* A different scenario arises in patients suffering from progressive neurodegenerative conditions, such as amyotrophic lateral sclerosis (ALS) or advanced Alzheimer's disease, where long-term artificial nutrition may eventually become necessary due to the gradual loss of swallowing function. In these circumstances, the decision whether to initiate ANH may legitimately be

[5] For a comprehensive ethical reflection on this issue see for example, Lisa S Cahill, "Bioethics," Theological Studies, 67 (2006): 120-142.

[6] For a detailed examination of the shift from ANH being basic care to becoming medical means, see James T. Bretzke, "A Burden of Means: Interpreting Recent Catholic Magisterial Teaching on End-of-Life," Journal of the Society of Christian Ethics, Vol. 26, No. 2 (2006): 183-200.

made by the patient while still competent, particularly in light of the increased risk of aspiration associated with oral feeding. Advance medical directives may play an important role in this context by enabling patients, while still deemed capable of informed decision-making, to express their preferences regarding the initiation or continuation of artificial nutrition should they later lose decision-making capacity. Such directives could provide legally binding direction to healthcare professionals and family members when complex clinical decisions must be made in the later stages of illness.

However, once initiated, the ethical significance of ANH may change as the underlying disease progresses. An intervention that is initially introduced as supportive care may, over time, function primarily as a life-prolonging measure, particularly if the burdens associated with it may increase as the patient's condition deteriorates. For this reason, advance medical directives should not be interpreted as rigid instructions applicable irrespective of the clinical situation, but rather as expressions of the patient's values and treatment preferences that must be interpreted prudently within the evolving medical context.

While the non-initiation of ANH may be ethically permissible when its burdens are considered to outweigh its potential benefits, the withdrawal of ANH once established may present complex ethical, clinical, and practical challenges, especially where it continues to sustain life. Such decisions should therefore be guided by careful clinical judgement and ethical reflection, with due regard to the patient's condition, prognosis, previously expressed wishes, and whether continued ANH remains proportionate, beneficial, and aligned with the overall goals of care.

c. *Artificial nutrition and nutrition in the terminally-ill patient*: A third scenario concerns patients who are already in the final stages of the dying process. This is where the ethical difficulty lies, since it may be challenging to determine when a patient has reached the final stages of the dying process rather than experiencing a potentially reversible clinical deterioration. Therefore, after having collected all medical data, the medical team together with the relatives must be able to agree on whether the patient is merely passing through a reversible medical crisis, or whether the patient is actually dying. In such cases, the administration of ANH may no longer serve the physiological purposes associated with nourishment and recovery. As the body's systems progressively fail, patients may lose the capacity to metabolise fluids and nutrients effectively.[7] Under these circumstances, the continued administration of ANH may not only fail to provide benefit but may also contribute to additional discomfort, including fluid overload, respiratory complications, or gastrointestinal distress. In these situations, the ethical

[7] Shalini Dalal, Egidio Del Fabbro, Bruera Eduardo, "Is there a role for hydration at the end of life?" Current Opinion in Supportive and Palliative Care 3, no.1 (2009): 72-78. See also Alexandria J. Bear MD, Elizabeth A. Bukowy DO, Jayshil J. Patel MD, "Artificial Hydration at the End of Life," Nutrition in Clinical Practice 32, no. 5 (2017): 628-632, and American Society for Parenteral and Enteral Nutrition, "A.S.P.E.N. Ethics Position Paper," Nutrition in Clinical Practice, 25, no. 6 (2010): 672-679.

focus of care appropriately shifts from sustaining physiological functions to providing comfort and alleviating suffering.[8]

Good palliative care, therefore, prioritises symptom management, meticulous oral care, and the provision of psychological, social, and spiritual support to both the patient and their family. Recent clinical evidence supports a personalised and holistic approach to decision-making in such cases, recognising that end-of-life care must take into account not only physical considerations but also the broader human needs of the patient and those accompanying them during the final stages of life.[9]

For this reason, any advance medical directive addressing ANH should recognise the diversity of clinical circumstances that may arise and allow for careful case-by-case evaluation by healthcare professionals, ideally in dialogue with the patient's designated representatives.[10]

22. *Respect for Patient Autonomy and its Limits:* One of the central ethical principles underlying an advance medical directive is respect for patient autonomy. Autonomy refers to the capacity of individuals to make informed decisions regarding matters that affect their lives, including their healthcare. Advance medical directives are intended to safeguard this autonomy by allowing individuals to express their treatment preferences in advance, particularly in situations where they may later lose decision-making capacity. However, the principle of autonomy cannot be understood in an absolute or purely individualistic manner. Medical decisions always take place within a relational context that involves healthcare professionals, family members, and the broader healthcare system. For this reason, the exercise of autonomy must be balanced with other ethical principles, including dignity, integrity, justice and vulnerability.

    The Bill strongly emphasises respect for patient autonomy by allowing competent adults to refuse specified medical treatments in advance. At the same time, the

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[8] Congregation for the Doctrine of Faith, Responses to Certain Questions of the United States Conference of Catholic Bishops concerning Artificial Nutrition and Hydration (2007): https://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_20070801_risposte-usa_en.html. See also Commentary Artificial Nutrition and Hydration: https://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_20070801_nota-commento_en.html and Directive 58 of the United States Conference of Catholic Bishops' Ethical and Religious Directives for Catholic Health Care Services (2001): "*In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g., the "persistent vegetative state") who can reasonably be expected to live indefinitely if given such care. Medically assisted nutrition and hydration become morally optional when they cannot reasonably be expected to prolong life or when they would be "excessively burdensome for the patient or (would) cause significant physical discomfort, for example resulting from complications in the use of the means employed." For instance, as a patient draws close to inevitable death from an underlying progressive and fatal condition, certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort."* https://www.ncbcenter.org/resources-and-statements-cms/revision-of-directive-58-of-ethical-and-religious-directives-for-catholic-health-care-services

[9] Davies, Andrew, Caroline Barry, and Stephen Barclay. "What is the Role of Clinically Assisted Hydration in the Last Days of Life?" BMJ : British Medical Journal (Online) 380, (2023).

[10] Hasan Hazim Alsararatee, "The Ethics of Clinically Assisted Nutrition and Hydration in Adults and the Role of the Advanced Clinical Practitioner," British Journal of Nursing 33, no. 13 (2024), and Mircea Stoian, Adina Stoian, and Claudia Bănescu et al., "Nutrition and Hydration at the End of Life in Intensive Care and General End-of-Life Care Settings: Balancing Clinical Evidence, Patient-Centered Care, and Ethical and Legal Principles—A Narrative Review," Nutrition, 17, no. 33 (2025): 3705.

Bill introduces important limits. For example, directives do not apply when the patient retains decision-making capacity, and they are only applicable when the clinical circumstances correspond to those specified in the directive (clause 7(2)). Furthermore, the Bill states that instructions contrary to law shall be null and void (clause 3(3)). This provision reflects the ethical principle that autonomy does not extend to requiring healthcare professionals to perform actions that are medically inappropriate or morally unacceptable. The legislation thus attempts to balance respect for individual self-determination with the professional responsibilities of healthcare providers.

23. *The Distinction between Allowing Natural Death and Euthanasia*: A recurring ethical concern in debates surrounding advanced medical directives is the risk that they may be misinterpreted as instruments facilitating euthanasia or assisted suicide. The Bill addresses this concern by limiting directives primarily to refusals of treatment rather than requests for active interventions aimed at causing death. From an ethical standpoint, this distinction is crucial. Refusing disproportionate or burdensome treatment allows the underlying illness to take its natural course, whereas euthanasia involves intentional action directed toward causing death. Maintaining this distinction ensures that the legislative framework supports responsible end-of-life care while avoiding practices that would undermine the ethical foundations of medicine.

    It is therefore essential to maintain a clear ethical and legal distinction between allowing natural death and intentionally causing death. Allowing natural death refers to the decision to withhold or withdraw medical interventions that are disproportionate, excessively burdensome, or no longer beneficial to the patient. In such cases, death results from the underlying illness rather than from an intentional act aimed at ending life. Euthanasia, by contrast, involves an intentional act or omission whose primary purpose is to bring about the patient's death in order to eliminate suffering.

    Clause 3(3) of the Bill, which renders null and void any stipulation requiring an omission, instruction, or practice contrary to law, constitutes an important safeguard ensuring that advance medical directives cannot be interpreted as authorising actions whose purpose would be to intentionally hasten death. The ethical perspective underlying this position paper holds that such actions are morally unacceptable insofar as they contradict the fundamental commitment of healthcare to the preservation and protection of human life and the duty to care for the vulnerable.[10] Advance medical directives must therefore be carefully framed so as to support ethically appropriate end-of-life care (including the patient's legitimate refusal of disproportionate or excessively burdensome treatment) while avoiding interpretations that could facilitate practices aimed at intentionally hastening death.

24. *Protection of Vulnerable Persons:* Another critical ethical concern in the introduction of advance medical directives is the protection of vulnerable individuals. These may include elderly persons, individuals with disabilities, patients suffering from cognitive impairment, or persons who may feel themselves to be a burden on their families or on society. The procedural safeguards contained within the Bill help address this issue in several ways. Research conducted in jurisdictions where advance directives have been

implemented indicates that social pressures, whether explicit or implicit, can sometimes influence decisions regarding life-sustaining treatment.[11] Vulnerable individuals may feel compelled to refuse treatment in order to avoid being perceived as a burden.

For this reason, legislation regulating advance medical directives must include strong safeguards to ensure that such directives are genuinely voluntary and free from coercion. Particular attention should be given to ensuring that individuals receive appropriate information regarding their medical options, including access to palliative care and psychological support. Safeguards should also ensure that advance medical directives cannot be used in ways that discriminate against individuals on the basis of age, disability, or perceived quality of life. Continued vigilance is necessary to ensure that vulnerable persons are not subjected to subtle pressures that might influence decisions regarding life-sustaining treatment, and that advance medical directives cannot be used in ways that discriminate against individuals on the basis of age, disability, or perceived quality of life.

25. In this regard, the adequacy of Malta's palliative care infrastructure deserves specific attention. Despite advances in medical care and increasing recognition of the importance of palliative approaches, a substantial proportion of patients continue to experience unmet palliative needs at the end of life. It has been estimated that up to 200,000 patients in the United Kingdom alone lack access to adequate palliative care, with as many as one-third experiencing poorly controlled symptoms and insufficient clinical support in their final months.[12] If palliative care services are insufficiently developed, there is a real risk that patients may feel compelled to issue advance refusals of treatment in the absence of meaningful alternatives. The introduction of the Bill should therefore be accompanied by a parallel commitment to developing palliative care capacity, ensuring that the choice to refuse treatment reflects genuine patient preference and not the absence of adequate supportive care.

26. *The Role of Family Members and Surrogate Decision-Makers:* Although advance medical directives are designed to express the wishes of the patient, designated representatives often play an important role in end-of-life decision-making. In many cases, designated representatives are those who best understand the patient's values, beliefs, and preferences, and their involvement can therefore provide important contextual insight when difficult clinical decisions arise.

    Within the framework established by the Bill, the focus is placed primarily on the directive itself as the authoritative expression of the patient's prior wishes. Nevertheless, Schedule 1 allows the 'appearer' to designate an 'appointed' person. Although this person does not possess the authority to alter or vary the

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[11] Harvey Max Chochinov et al., "Burden to Others and the Terminally Ill," Journal of Pain and Symptom Management 34, no. 5 (2007): 463–471.

[12] T. Johansson et al., "Defining and Measuring Unmet Palliative Care Needs among People with Life-Limiting Illness: A Scoping Review of International Evidence," Palliative Medicine, advance online publication (2026), https://doi.org/10.1177/02692163261416279. See also A. E. Bone et al., "Coproducing a Conceptual Understanding of Unmet Palliative Care Needs: Stakeholder Workshops Using Modified Nominal Group Technique," BMC Palliative Care (2025), https://doi.org/10.1186/s12904-025-01971-4.

directive, his or her role may nonetheless be important in communicating the patient's values and assisting healthcare professionals in interpreting the directive within complex clinical circumstances. The role of this appointed person, what this person should be notified about, and what 'if required' means, is not specified in the Bill. This is a missed opportunity to introduce and regulate the appointment of a durable power of attorney for healthcare.

Here, however, a further concern arises. Clause 6(2) of the Bill restricts access to a directive exclusively to the treating medical practitioner. This confidentiality provision, while necessary to protect patient privacy, may in practice limit the ability of loved ones and the 'appointed' person to engage meaningfully in end-of-life decisions. We recommend that clause 6(2) is amended to allow a designated person to access information about the existence and terms and conditions of a directive, without compromising the confidentiality of sensitive medical data.

At the same time, the role of loved ones and designated representatives must be carefully defined in order to avoid potential conflicts of interest or disagreements among relatives. Clear legal and ethical guidance is therefore necessary to ensure that the patient's previously expressed wishes remain the primary reference point for decision-making. Encouraging open dialogue among patients, families, and healthcare professionals through advance care planning can significantly reduce the likelihood of conflict and facilitate more compassionate and ethically responsible end-of-life care.

Finally, attention must be drawn to clause 10 of the Bill, which preserves the legal and clinical effect of existing DNR orders issued by medical practitioners, provided they were made following a contemporaneous clinical assessment and are recorded in medical records. While the preservation of DNR orders is practically necessary, it highlights the importance of ensuring that such orders are made in genuine dialogue with patients and their families. The introduction of the Bill should prompt a broader review of DNR practices in Malta, ensuring that they reflect the same standards of informed consent, voluntary decision-making, and clinical transparency that the Bill now requires for advance medical directives.

Part IV: Recommendations

27. In light of the ethical and legal considerations outlined above, a number of recommendations may be proposed for the development of legislation regulating advance medical directives in Malta:

a) *Renaming the draft Bill*: We recommend that the Bill use currently accepted terminology, both in its title, and in its contents, and thus propose that the phrase ‘advanced medical directive’ be changed to ‘advance medical directive’ throughout.

b) *Promoting advance care planning rather than merely written directives*: While recognising the value of giving legal backing to an individual’s expressed wish to refuse certain medical treatment in specified circumstances, we encourage the government and relevant stakeholders to promote and encourage advance care planning as an ongoing communicative process.

c) *Ensuring informed and voluntary consent:* We note that the law, as drafted, seeks to safeguard informed and voluntary refusal by requiring the presence of both a medical practitioner and a notary. Nevertheless, the validity of an advance medical directive should rest on clear evidence that it was made voluntarily and with adequate information. This entails ensuring that individuals are properly informed about the medical implications of their decisions, including the availability of palliative care and other supportive services, while also promoting broader dissemination of awareness of such support.

d) *Establishing clear safeguards and review mechanisms*: Clause 7(1) provides that a directive remains valid indefinitely unless it is revoked or amended. This raises the ethical concern that a directive made years or even decades before the relevant moment may no longer accurately reflect the patient’s values, particularly if the patient has undergone significant changes in worldview or personal values, or where the progression of a chronic illness has altered their experience of suffering and their attitude toward life-sustaining treatment. A statutory periodic review mechanism — for instance, every five years — is recommended as a safeguard against the entrenched application of directives that no longer reflect the patient’s current wishes or circumstances.

e) *Encouraging the appointment of healthcare proxies*: The Bill does not provide for a durable power of attorney for healthcare or any formal healthcare proxy mechanism. This is a significant lacuna. The legal framework should encourage individuals to appoint a trusted healthcare proxy who can interpret their wishes in complex medical situations that may not have been anticipated when the directive was drafted. Reference to comparative legislative models in jurisdictions such as Germany, Spain, France, and England may be instructive in this regard.

f) *Introducing a conscience clause*: The Bill contains no provision for conscientious objection by healthcare professionals. This omission creates legal uncertainty and should be remedied by the introduction of an explicit conscience clause, accompanied by mechanisms to ensure that patients receive continuity of care when a practitioner conscientiously objects.

g) *Establishing a clinical ethics consultation mechanism*: Given the complexity of end-of-life clinical situations and the inadequacy of judicial proceedings as a primary dispute resolution mechanism, a clinical ethics consultation service should be established as a first-resort alternative to court referral. Such a service would provide timely, multidisciplinary ethical guidance to healthcare teams and families facing difficult decisions.

h) *Providing clinical guidance on the correspondence requirement and ANH*: Implementing regulations or clinical guidelines should address the risk that clause 7(2)(b)'s correspondence requirement is interpreted too mechanically, and should provide guidance on the clinical and ethical implications of separately refusing artificial nutrition and artificial hydration.

i) *Integrating advance medical directives within a strong palliative care framework*: The introduction of advance medical directives should not be viewed in isolation but should form part of a broader commitment to strengthening palliative care services in Malta. Access to high-quality palliative care ensures that patients approaching the end of life receive appropriate symptom management, psychosocial support, and spiritual care, and that advance refusals of treatment reflect genuine preference and not the absence of adequate alternatives.

j) *Safeguarding clinical judgement in the absence of advance directives*: In addition to clause 8(2) of the Draft Bill, we strongly recommend the inclusion of a provision to ensure that, in cases where patients do not have advance medical directives, medical practitioners do not incur civil or criminal liability for acting in accordance with best medical practice, hospital standard operating procedures, or recognised clinical practice guidelines. This protection should apply when discussing end-of-life care management plans with either patients or their proxies and when proceeding to withhold or withdraw any medical therapies deemed excessively burdensome or medically inappropriate. In such situations, patient-centred decision-making should be guided by a holistic assessment of the individual's values, preferences, clinical condition, and overall goals of care. Such an approach promotes consistency and equity, while helping to avoid unintended disparities in care.

k) *Reviewing DNR practices*: The introduction of the Bill should prompt a broader review of DNR order practices in Malta, ensuring that such orders meet the same standards of informed consent and transparency as are now required for advance medical directives. Medical practitioners shall not incur any civil or criminal liability for acting in accordance with a valid DNR decision.

l) *Ensuring that the endurable power of attorney complies with the Advanced Medical Directives Act*: A consequential amendment is needed to article 1864A of the Civil Code regulating durable powers of attorney so that the latter, if introduced, complies with the provisions of the Advanced Medical Directives Act, 2026.

m) *Establishing the criteria for assessing mental incapacity:* Although clause 4(3) refers to a medical practitioner assessing the mental capacity of the appearer, the provision does not state how this will be done, nor does it refer to any current medical practice or guidance that is used in such circumstances, nor does it

empower the making of regulations to this effect. If the exact procedure is not spelt out or referred to, then certain medical practitioners might adopt different criteria. If there are any extant government or professional directives to this effect, a mention thereof should be made. But it would always be better if these assessment methods are adopted by regulations for the purpose of accessibility.

n) *Creating a mechanism for notifying the mental capacity assessment*: Consideration should be given to establishing a formal mechanism for recording the outcome of mental capacity assessments conducted for the purpose of executing an advance medical directive. Situations may arise in which an individual who has been assessed by one medical practitioner as lacking the necessary decision-making capacity subsequently seeks certification from another practitioner. In the absence of any system for recording prior assessments, such discrepancies may go unnoticed. It is therefore recommended that medical practitioners who conduct a mental capacity assessment for this purpose forward a record of their conclusions to the Director General for Health Care Services for registration. Such a mechanism would enable the relevant authority to identify conflicting assessments where they arise and to take appropriate action where necessary, thereby strengthening the integrity and reliability of the certification process.

o) *Ensuring the validity of the advance medical directive:* Clause 5(7) provides that an advance medical directive becomes valid upon its authentication by a notary, rather than upon its registration or transmission to the relevant authority. This procedure may give rise to concerns about possible abuse or the risk that the directive could be tampered with. Moreover, it is possible that the notary may fail to transmit the directive to the Director General for Health Care Services within the legally established fifteen-day period. In such circumstances, the Director General would not be aware of the directive and therefore would not be in a position to ensure that it is complied with. This situation is further complicated by the possibility that the designated 'appointed' person may also be unaware that the appearer had drawn up an advance medical directive. To avoid such difficulties, it would be preferable for the directive to take effect only once it has been received by the Director General for Health Care Services. Ideally, the designated person should also be notified, within the same fifteen-day period, and provided with a copy of the directive. This would ensure that this person is informed of its contents in advance, rather than being confronted with it unexpectedly at emotionally sensitive and delicate moments when the directive becomes operational.

p) *Providing the appearer's declaration of ethical values*: For the purpose of facilitating interpretation, we suggest that the appearer may choose to include in the advance medical directive a clarification of his or her ethical values, for example by referring to a particular religion, belief system, or philosophical outlook. This could assist in interpreting the appearer's intentions in situations where the directive may not be entirely clear.

Conclusion

28. The Bill represents a significant development within the Maltese healthcare system by providing a clear legal framework governing advance refusals of medical treatment. By establishing procedures for the preparation, authentication, registration, and implementation of directives, the Bill offers both legal certainty and ethical safeguards. Nevertheless, legislation alone cannot resolve the complex moral questions associated with end-of-life care. The effectiveness of the Bill will ultimately depend on how it is interpreted and implemented within clinical practice, and on the extent to which it remains integrated within a broader ethical commitment to respect for human dignity, compassion, and responsible medical care.

29. If developed within such a framework, advance medical directives can serve not only as legal instruments but also, for instance, as expressions of thoughtful and humane preparation for the final stages of life. As this position paper has sought to argue, advance medical directives cannot be understood merely as legal documents expressing individual preferences. Rather, they must be situated within a broader ethical framework that recognises the relational nature of healthcare decision-making, the responsibilities of healthcare professionals, the legitimate role of representatives nominated by the patient or otherwise appointed in accordance with the law, and the need to protect persons making advance medical directives from potential forms of coercion or neglect. Respect for patient autonomy, while fundamental, must therefore be balanced with other ethical principles, including beneficence, non-maleficence, justice, and the broader social commitment to the protection of human life and dignity.

30. Ultimately, the challenge facing policymakers is not simply to regulate advance medical directives, but to foster a healthcare culture in which compassion, prudence, and respect for human dignity remain central to clinical practice. If developed within such an ethical framework, advance medical directives can become an important instrument for promoting responsible end-of-life care, supporting families and healthcare professionals in difficult decisions, and strengthening the solidarity that underpins a humane and just healthcare system.

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