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Consensus Statement on Dignity in Illness, Disability, and Dying

and a Response to the UNESCO Universal Draft Declaration on Bioethics and Human Rights[a]

Colloquium of the International Association of Catholic Bioethicists

INTRODUCTORY REMARKS[b]

History of the International Association of Catholic Bioethicists. In July 2003, bioethicists from nineteen countries participated in a colloquium on "Globalization and the Culture of Life" in Toronto, Canada. On the last day of this colloquium, participants discussed ways to foster dialogue and collaboration among Catholic bioethicists. The idea of the International Association of Catholic Bioethicists (IACB) took root, and over the next six months, a committee of bioethicists began consultations to develop plans for such an organization. This committee thought it appropriate to approach the national associations of the Order of Malta for support because the Canadian Association of the Order of Malta had sponsored the Toronto colloquium. Moreover, the goals of the IACB are consonant with those of the Order, which has a long tradition of service worldwide to "our Lords, the sick".

In 2004, the IACB was established under the aegis of national associations of the Order of Malta, and support was provided for a secretariat of the IACB in Toronto. Individual associations of the Order, beginning with the Australian Association, also committed to sponsoring international bioethics colloquia in their countries. These colloquia are held every two years. The most recent IACB colloquium took place in Melbourne, Australia, in June 2005. Although funding for the IACB comes from national associations of the Order of Malta, the independence of the IACB's academic work is recognized and protected by the Order. Moreover, bioethicists who are associates of the IACB do not have to be members of the Order of Malta.

Purpose of the International Colloquia. A few words generally about the IACB international colloquia will help to clarify the process by which the following consensus statement from the most recent colloquium in Melbourne was generated. In selecting the theme and topics for discussion at a colloquium, particular consideration is given to unresolved questions from previous colloquia, new questions that have not yet been addressed by Church teaching, foundational issues in bioethics that are being vigorously debated, and issues of worldwide significance. The purpose of the colloquia, then, is to advance thinking on these questions and issues. For instance, the overall theme of the Melbourne colloquium and the topic of the first day of discussions was "dignity in illness, disability, and dying". The two papers commissioned for that day addressed, among other things, the question of whether refusing or discontinuing treatment of disabled patients is sometimes compatible with respect for the intrinsic dignity of these persons. This addressed a dispute that had been left unresolved at a previous colloquium, namely, what may be included in the consideration of a treatment's burden (paragraph 7 and note 7 below). The second day of the Melbourne colloquium dealt with issues emerging from the growing incursion of the market into the provision of health care in both developed and developing countries. Discussions of the two commissioned papers for that day helped to identify some ethical guidelines for

a. "Consensus Statement on Dignity in Illness, Disability, and Dying and a Response to the UNESCO Universal Draft Declaration on Bioethics and Human Rights" was the product of a Colloquium of the International Association of Catholic Bioethicists (IACB), held in Melbourne, Victoria (Australia), June 26–30, 2005.

b. *An introduction to the consensus statement is provided here by* William Sullivan, M.D., Ph.D., Medical Services, Surrey Place Centre; Family Practice Unit, St. Michael's Hospital (Toronto); affiliated teaching centers of the University of Toronto; and Director, International Association of Catholic Bioethicists.

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evaluating systems of health-care provision (paragraphs 24 to 28 below). Finally, an issue of worldwide significance has been the effort by UNESCO (United Nations Educational, Scientific and Cultural Organization) to put forward a declaration on bioethics. From the discussions on the final day of the Melbourne colloquium, a response to some of the statements in the latest version of this declaration was generated (Part Three below).

Structure of the International Colloquia. Openness to a range of well-considered viewpoints is one striking feature of the international colloquia. The structure of a typical colloquium fosters this openness in five ways. First, authors of papers for the colloquium are generally selected to represent contrasting positions on particular questions. Second, participants in the colloquium read the commissioned papers prior to arrival, so that most of the time in the colloquium itself is spent in small-group and plenary discussions. Third, participants are chosen from among professionals in various health sciences, social sciences, the humanities, and theology, so that there is a range of disciplines relevant to bioethics represented. Fourth, on account of the diverse countries and continents from which participants hail, discussion often arises on the bearing that cultural, socioeconomic, and political factors have on the topics being discussed. Fifth, there has been active participation in past colloquia by representatives of various Christian denominations and different religions as well as non-religious scholars who share a concern for respecting the dignity of the human person in society.

A strong emphasis is placed in the international colloquia on identifying points of agreement and disagreement. In the consensus statement from the Melbourne colloquium, for example, points of concurrence are expressed in the text, whereas significant questions that were left undiscussed or unresolved appear in the footnotes (see notes 1, 5, and 6 below). These footnotes are significant because they identify some of the questions that can be taken up for further research, reflection, and discussion by associates of the IACB and by others.

Often, an important part of the discussions at a colloquium is clarifying and agreeing on the meanings of terms. Confusion is sometimes generated and misunderstandings easily arise in bioethics because the same words or notions are used in different ways or out of their proper context. If the colloquia were to accomplish little else than to contribute toward the gradual development among Catholic bioethicists of a standard vocabulary and a common understanding of terms and notions, this alone would be a monumental advance. At the Melbourne colloquium, for instance, participants examined and discussed the meaning of terms such as "dignity" and "repugnance". Luke Gormally urged participants to distinguish between "lifesustaining" and "life-prolonging" treatments. There was some debate on this point but no time to resolve it. Gormally's intervention, however, did result in more precise use of the term "treatment" in the consensus statement (note 1 below). A further illustration of the need for clarity is Daniel Sulmasy's thought-provoking argument, set out in a paper he wrote for the colloquium, that the decision to refuse or withdraw extraordinary treatment should not be considered in terms of the principle of double effect. Although this philosophical point was not taken up in the discussions, several of its practical and ethical implications were considered (paragraphs 6, 7, and 11 below).

Another constructive outcome of the discussions at a colloquium is coming to a better understanding of some of the foundational issues that continue to unite and divide Catholic bioethicists. For example, at the Melbourne colloquium, there was universal acceptance of three fundamental truths about the human person: intrinsic dignity, interdependency, and finitude (paragraphs 2 to 4 below). There was agreement that the Church's social teaching, especially on the common good, distributive justice, the preferential option for the poor, and subsidiarity, constitutes an important basis for Catholic bioethics. These common starting points, variously elaborated in the papers written by Bishop Anthony Fisher, Fr. Stephen Fernandes, and Helen McCabe, helped to shape the discussions at the colloquium. Much of what is affirmed in the consensus statement is based on these principles. On other issues, however, there was no general consensus. For instance, there was no agreement on whether, in ethical deliberation about life-prolonging treatment, it is valid, without reference to the condition of particular patients, to classify some kinds of treatment as in principle ordinary and morally obligatory, so that there should always be a presumption in favor of their initiation or continuation (note 6 below). What seems to underlie this dispute is the more basic issue of whether ethical justification and deliberation should proceed from general principles to particular cases, or vice versa.

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All such discussions at a colloquium, especially when they touch on matters of fundamental importance to participants, can be fueled by enthusiasms and fraught with tensions. The organizers of these international colloquia, therefore, try to foster a milieu for discussion that is prayerful and collegial, and to attend as much as possible to various personal and social factors that are involved in the generation of knowledge. Often, listening to one another and to God turns out to be as important as speaking at these colloquia. There is daily celebration of the Eucharist and participation in morning prayer, as well as opportunities to socialize and deepen friendships among bioethicists. Although a multiplicity of languages can be heard at these social gatherings, the common language of the colloquium proceedings is English.

The Next International Colloquium. The next IACB international colloquium will be held in London, England, in 2007. It is hoped that similar discussions and collaborations among associates of the IACB can take place within their own regions or countries. For more information about the IACB and its work, please access the IACB Web site at http://www.iacbweb.org, or send an e-mail message to secretariat@iacbweb.org. The four papers commissioned for the Melbourne colloquium will be published and also made available on the IACB Web site.

William Sullivan, M.D., Ph.D.

Colloquium of the International Association of Catholic Bioethicists (IACB): Consensus Statement on Dignity in Illness, Disability, and Dying

and a Response to UNESCO's Universal Draft Declaration on Bioethics and Human Rights

INTRODUCTION

1. The Australian Association of the Order of Malta and the John Paul II Institute sponsored a colloquium of the IACB in Melbourne from June 26 to 30, 2005. Forty bioethicists from thirteen different countries, as well as knowledgeable guests and students, participated. In light of the colloquium's theme of "dignity in illness, disability, and dying", the bioethicists discussed some questions concerning the understanding and application of the Church's teachings on life-prolonging treatments[1] and some emerging questions on the ethical evaluation of systems of health-care provision. Prior to the colloquium, participants read four commissioned papers that identified key issues for discussion in small groups and in plenary sessions[2]. The discussions then informed the writing of this consensus statement, which has three parts.

The first two parts summarize main principles agreed upon by most participants in the Melbourne colloquium. A few footnotes explain points of divergence among the participants[3]. These considerations are offered to bioethicists to advance thinking about life-prolonging treatments and the evaluation of systems of health-care provision, as well as to identify some questions that stand in need of further study, reflection, and discussion. The third part of this statement is a response to UNESCO's "Draft Universal Declaration on Bioethics and Human Rights"[4]. This response is offered to provide some guid-

1. Some participants in the colloquium argued that one ought to distinguish between *life-prolonging* treatment, understood as care administered in response to an immediate, life-threatening medical crisis, and *life-sustaining* treatment, understood as care necessary to keep a patient alive in the absence of any such crisis. On this view, repugnance about a state of life, such as living with a chronic illness or disability, could never justify refusing any life-sustaining treatment. After discussion of this point, participants in the colloquium agreed to use the term "life-prolonging treatment" throughout this statement, and to leave open for further reflection and discussion whether Catholic teaching on ordinary and extraordinary means of care presupposes a distinction between life-prolonging and life-sustaining treatments. On artificial nutrition and hydration as a possible special case, see note 6 below.

2. Anthony Fisher, "Why Do People Who Cannot Exercise Rational Autonomy Matter?"; Daniel Sulmasy, "Double Effect Reasoning and Care at the End of Life: Some Clarifications and Distinctions"; Stephen Fernandes, "Ethical Challenges for the Christian Community in the Just Distribution of Health Care"; and Helen McCabe, "An Ethical Evaluation of Managed Care: A Beginning".

3. John Heng wrote the draft of the first two parts of the consensus statement, with helpful input from Ray Campbell, William Sullivan, Fr. Norman Ford, and Daniel Sulmasy. Participants in two plenary sessions of the colloquium assisted in the editing of this draft.

4. UNESCO, "Draft Universal Declaration on Bioethics and Human Rights" (Paris, June 24, 2005; http://unesdoc.unesco.org/images/0014/001402/140287E.pdf). Bernadette Tobin and Fr. John Fleming wrote a response to the February 9, 2005, version of the UNESCO document titled "Preliminary Draft Declaration on Universal Norms on Bioethics", with input from Fr. No'l Simard. This document was discussed by participants in the Melbourne colloquium. On the basis of the participants' comments, Bernadette Tobin and Fr. John Fleming then revised their draft to take into account the text of a later version of the UNESCO document, titled "Draft Universal Declaration on Bioethics and Human Rights" (June 24, 2005), which was made public after the Melbourne colloquium.

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ance to those called upon to interpret and apply the principles contained in the universal declaration.

Participants had various opportunities to contribute to the content and form of all three parts of the consensus statement, and each participant was given the option of attaching his or her name to the statement.

PART ONE: LIFE-PROLONGING TREATMENTS

Human Dignity, Interdependency, and Finitude

2. Every human being has intrinsic dignity. This dignity is based on the kind of being a human person is, namely, a created unity of body and spirit. Theologically, we hold that human beings have dignity because they have been created in the image and likeness of God. Characteristics such as the capacity to be self-reflective, to reason, to communicate, to choose freely and responsibly on the basis of conscience, to give and receive love, and to worship and be in friendship with God set humankind apart from other forms of life. Even if one or more of these capacities in a human being are diminished or cannot be observed, he or she never loses intrinsic dignity. That individual remains a being that has a rational nature.

3. A related truth can be expressed in terms of human interdependency. Each human being throughout life is related to, and dependent on, others in the human community. An individual who is vulnerable or dependent because illness, disability, or age has affected his or her cognitive functions is still a member of the human community. Dependency does not diminish the dignity of the individual. Indeed, it is in looking after vulnerable and dependent individuals that the highest expression of human solidarity and the Church's preferential love for the sick and needy can be realized in health care.

4. As a unity of body and spirit, human beings are finite and mortal beings. The duty to sustain one's earthly life has limits. The Catholic tradition allows for withholding or withdrawing life-prolonging treatments in some circumstances. A decision by a patient to forgo a treatment that promises no hope of benefit or is excessively burdensome to the patient or another is not a choice to commit suicide.

Benefits and Burdens of Life-Prolonging Treatments

5. The terms "ordinary" and "extraordinary" have been used in philosophy and theology in the Catholic tradition to articulate judgments of the limits of an individual's moral duty to prolong life[5]. In this usage, a life-prolonging treatment that is ordinary is morally obligatory, and one that is extraordinary may be forgone[6].

6. In judging what is an ordinary or extraordinary means in a given circumstance, the perspective of the patient is primary. Such a judgment involves considering evidence for the benefits and burdens of a given medical treatment or treatments for that person.

7. The condition of the patient after a proposed treatment, i.e., the effects that the treatment is likely to have on the patient's overall well-being, can be part of the consideration of the treatment's benefits and burdens, and

5. In 1957, Pope Pius XII stated that the use of ordinary means for conserving life and health was morally necessary. His clarification of the morally relevant meaning of ordinary and extraordinary means in relation to patients and others is balanced and remains relevant today: "…normally one is held to use only ordinary means – according to circumstances of persons, places, times, and culture – that is to say, means that do not involve any grave burden for oneself or another. A more strict obligation would be too burdensome for most men and would render the attainment of the higher, more important good too difficult. Life, health, and all temporal activities are in fact subordinated to spiritual ends". See Pius XII, "Address to an International Congress of Anesthesiologists", *L'Osservatore Romano* (November 25–26, 1957). An interesting and rich discussion emerged in the Melbourne colloquium on a point made in Daniel Sulmasy's paper, that the distinction between ordinary and extraordinary means of care should not be understood as an application of the principle of double effect. The colloquium did not, however, take this up as a question for debate.

6. The colloquium as a whole did not specifically address the issue of artificial nutrition and hydration (ANH). John Paul II addressed this topic in a speech on March 20, 2004, to participants in the International Congress on "Life Sustaining Treatments and the Vegetative State", sponsored by the World Federation of Catholic Medical Associations (FIAMC) (reprinted in *National Catholic Bioethics Quarterly* 4.2 [Summer 2004]: 367–370). Part of Anthony Fisher's paper for the Melbourne colloquium defended the view that the duty to feed has deep roots in Christian theology, spirituality, and ethics. A broader fundamental question in ethics emerged during discussions at the colloquium, namely, whether it is valid, *without reference to the condition of particular patients*, to classify some kinds of treatment in principle as ordinary and morally obligatory, so that there should always be a presumption in favor of their initiation or continuation. For bioethicists who argue in favor of this position, moral reasoning about the duty to conserve one's life ought to proceed in two steps: first, one should determine whether or not the care proposed is of the *kind* that is morally obligatory in principle; next, one ought to judge whether what is morally obligatory in principle holds for a *particular* patient. They would argue that the delivery of ANH is an instance of the kind of care that is morally obligatory in principle, and would interpret the speech by John Paul II on March 20, 2004, as supporting this position. Other bioethicists do not distinguish between these two steps in moral reasoning but hold, rather, that treatments cannot be classified as ordinary or extraordinary ahead of time and without reference to the state of the patient. Clarity on the basis of diverging views on this general issue was an important achievement in the Melbourne colloquium, even though no agreement among participants was reached. Both sides in the dispute, however, admit the moral relevance of a patient's condition *at some point*, whether as the determining factor in decisions about any treatment or as a consideration in judging whether the norm in favor of choosing life-sustaining treatment applies in a concrete case. Thus, both sides in the dispute might concur that "while raising many principles of universal applicability, the recent papal speech particularly addressed ANH for people in a state of post-coma unresponsiveness ['persistent vegetative state']. However, in applying these principles to medical conditions from which the frail elderly are far more likely to suffer, such as Alzheimer's disease, Parkinson's disease, cancer, and stroke, it is important to note that these conditions differ in important ways from post-coma unresponsiveness". See Colloquium of the Canadian Catholic Bioethics Institute, "Reflections on Artificial Nutrition and Hydration", *National Catholic Bioethics Quarterly* 4.4 (Winter 2004): 780, n. 14; see also n. 7 on p. 779.

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could help to determine the limit of a person's moral duty to preserve his or her life[7].

8. In some situations, a patient might find it difficult to judge when the limit of the duty to conserve his or her life has been reached. There may be a great degree of uncertainty regarding the patient's present or future condition. Also, pre-existing or co-existing challenges such as depression, diminished cognition, and spiritual distress could impair the capacity of a patient to judge reasonably and responsibly. Nonetheless, a competent or capable patient's judgment should be respected.

Medical care should include assessing the presence of challenges that may diminish the capacity of a patient to judge responsibly, and providing resources to address such challenges. Examples of such resources are social support, counseling, ethical consultation, friendship, prayer, and pastoral care. Persons affected by illness and disability, and those who are approaching death, should be given the opportunity to develop morally and spiritually through these and other means.

9. Special care must be taken to inform the consciences of individuals in cultures in which suffering, nonproductiveness, and death are generally regarded as lacking meaning. It is important to clarify, through education, that the decision to refuse or to withdraw life-prolonging treatment should not be based on a judgment that a person's life is no longer "worth living" or that it no longer has value or dignity.

10. Care must be taken to ensure that an individual who is ill or lives with disabilities is not under-treated and neglected.

11. When an individual is incapable, because of diminished cognition, of deciding whether a life-prolonging treatment is ordinary or extraordinary, his or her representative should make a prudential judgment of the benefits and burdens for that person, informed by that person's known or presumed wishes.

12. An individual's judgment of extraordinariness has limits. Patients or their representatives have a duty to take into account challenges to their determinations regarding the extraordinary status of treatments if the community judges such determinations to lack prudence.

PART TWO: EVALUATION OF SYSTEMS OF HEALTH-CARE PROVISION

A Christian Understanding of Health Care in Light of Human Dignity, Interdependency, and Finitude

13. Health entails harmony within, and among, the biological, psychological, social, and spiritual aspects of a human being. In light of what has been said above concerning the finitude of human beings, health ought not to mean simply the elimination of illness or disability, or to imply that the ultimate goal of health care is to perfect the body or to prolong life indefinitely[8].

14. It follows from what has been said about the fundamental dignity of each human being that the care rendered to patients should never be treated as a market commodity, and that a patient's health ought never to be compromised in the pursuit of financial profit for others.

15. In light of the interdependency of each member of the human family, while the goal of medicine is the health of the patient, the patient's relationships with his or her family and community must be given due attention. The person receiving care is vulnerable and entrusts himself or herself to the benevolence of caregivers. At the same time, Christian health care recognizes that caregivers can "see the face of Christ" in encountering the elderly, the sick, those with a handicap, and the dying[9].

Thus, Christian health care seeks to protect and to promote trust and compassion in relationships between patients and caregivers.

7. This was a point of contention in an international colloquium of Catholic bioethicists in Toronto in 2004. See Colloquium of the Canadian Catholic Bioethics Institute, "Reflections on Artificial Nutrition and Hydration", 779, note 8. Although the Catholic tradition recognizes "repugnance" as a reason for judging a treatment to be "extraordinary", it has not clearly addressed the question of whether this ought to refer to the patient's repugnance about the burdens of the treatment itself or of the *effects* of that treatment, one of which would be the state of life in which the treatment leaves him or her. Agreement on point 7 in this statement represents an advance in understanding that was arrived at through the discussions in the colloquium in Melbourne.

8. See John Paul II, Message for the World Day of the Sick (Feb. 11, 2000), n. 13. See also the World Health Organization's definition of health: "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (preamble to the WHO Constitution, as adopted by the International Health Conference [June 19–22, 1946]; http://www.who.int/about/definition/en/).

9. Pontifical Council for Pastoral Assistance to Health Care Workers, *Charter for Health Care Workers* (Boston: Daughters of St. Paul, 1995), n. 2, quoting from various prior speeches of Pope John Paul II: "Health care activity is based on an interpersonal relationship of a special kind. It is 'a meeting between trust and conscience'. The 'trust' of one who is ill and suffering and hence in need, who entrusts himself to the 'conscience' of another who can help him in his need and who comes to his assistance to care for him and cure him. This is the health care worker. For him 'the sick person is never merely a clinical case' – an anonymous individual on whom to apply the fruit of his knowledge – 'but always a "sick person",' towards whom 'he shows a sincere attitude of "sympathy", in the etymological sense of the term'. This requires love: availability, attention, understanding, sharing, benevolence, patience, dialogue. 'Scientific and professional expertise' is not enough; what is required is 'personal empathy with the concrete situations of each patient'".

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Some Reflections on the Distribution of Health-Care Resources

16. Health-care resources should be distributed justly to meet the true needs of individuals and communities. The responsibility to care for all in society without exclusion is grounded in the dignity of the human person. Health care can contribute to human flourishing in important ways. Every human being should have adequate access to basic health care[10].

17. In promoting health care, developing countries may have different challenges than countries in the industrialized world, depending on their particular social and economic conditions. In these countries, many in the population are poor and have little or no access to basic health care. Moreover, the lack of adequate nutrition, clean water, sanitation, shelter, education, and other basic conditions for health makes the promotion of health care extremely difficult. There are also large numbers of people affected by preventable infectious diseases such as HIV/AIDS, measles, and malaria. These challenges are sometimes compounded by unjust economic and political structures nationally and internationally, and by misguided "aid" from foreign governments and organizations. These bodies should take into account the true needs and values of the people. Governments and health-care systems should promote sanitary conditions and vaccinations, as well as basic primary health care.

The Responsibility of Catholics for a Just Distribution of Health-Care Resources

18. Catholics have a responsibility to promote the just allocation of health-care resources not only within their own countries but also between countries.

19. Catholics have a responsibility to ensure good stewardship of health-care resources personally, in their institutions, and in their countries, as part of their concern for the just allocation of health-care resources.

20. Catholics must be advocates for the marginalized, the powerless, and the vulnerable, and ensure that, as much as possible, these disadvantaged members of society are given the opportunity and means to participate in making decisions about the allocation of health-care resources in their institutions, their countries, and the world.

21. The elderly, the dying, and other persons with complex or chronic illnesses and disabilities are a valuable part of the human community. Catholics should work to change language, attitudes, and behaviors that cause these individuals to be treated as unwarranted burdens on society's resources.

22. In keeping with the Catholic principle of subsidiarity, services that are best provided in families and local communities, such as education, disease prevention, and primary care, should be provided locally rather than in remote or centralized institutions and systems. Resources adequate for these purposes should be provided.

23. In keeping with the social teaching of the Church, especially the preferential option for the poor, Catholics should collaborate in all efforts aimed at addressing the scandalous, unjust gap in health-care resources between rich and poor countries as well as between the rich and poor within countries. This calls for education of the faithful and a new "creativity in charity"[11].

Ethical Guidelines for Evaluating Systems of Health-Care Provision

24. The financing of systems of health-care provision must be based on the centrality of the person in need of care. Any means of ordering a system of health-care provision in which the primary goal is to maximize profit is incompatible with good health care. Such a system orders the giving of care ultimately, not to the good of the person in need of care or to the common good, but to efficiency for the sake of material gain for a few.

25. Any system of health-care provision should ensure that decisions are made at the individual and local levels, where the effects of those decisions are experienced, and where individuals and communities are capable of, and responsible for, carrying out such decisions.

26. In organizing a system of health-care provision, potential conflicts of interest, i.e., health professionals' having duties both to the system funding care and to their patients, should be minimized. The trust that should exist between health-care professionals and their patients must be maintained in such a context.

27. In any system of health-care provision, the informed conscience of doctors, nurses, pharmacists, and other health-care professionals must be respected.

28. Health-care institutions also have fundamental moral commitments, and their integrity as institutions must not be violated by laws that would force them to act in ways that are contrary to their moral commitments.

10. For instance, health education, disease prevention, and primary care.
11. John Paul II, *Novo millennio ineunte* (January 6, 2001) (Boston: Daughters of St. Paul, 2001), n. 50.

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PART THREE: RESPONSE TO UNESCO'S DRAFT UNIVERSAL DECLARATION ON BIOETHICS AND HUMAN RIGHTS

29. The International Bioethics Committee (IBC) of the United Nations Educational, Scientific and Cultural Organization (UNESCO) has finalized a draft of a document titled "Draft Universal Declaration on Bioethics and Human Rights"[12], hereafter referred to as "Declaration".

30. Both UNESCO and the United Nations were founded on the ideas that the universal "recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world", that "disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of mankind", and that the "advent of a world in which human beings shall enjoy freedom of speech and belief and freedom from fear and want has been proclaimed as the highest aspiration of the common people"[13].

31. The Declaration is to be read against the background of international law found in the "Universal Declaration of Human Rights"[14] and the other four international human rights treaties that are jointly known as "The International Bill of Human Rights"[15].

32. It is therefore striking that, although situated within the context formed by the "Universal Declaration on Human Rights" and related documents, this Declaration is in parts inconsistent with what is said authoritatively about their proper interpretation. For instance, whereas the Human Rights Committee[16] specifically described the right to life as "the supreme right"[17], a right from which there can be no derogation[18], even in a "time of public emergency which threatens the life of the nation"[19], this Declaration makes no explicit reference to such a right but talks merely of "ensuring respect for the life of human beings" (Article 2 (iii)).

33. Much of what is in the Declaration is welcome, in particular its emphasis upon the respect for the dignity of the human person (Preamble), its recognition of human rights (Article 3 et al.) and of the obligations that justice imposes on us (Article 10).

Comments on *Preamble to Declaration*

34. We note the claim that "scientific and technological developments have been, and can be, of great benefit to humankind in increasing *inter alia* life expectancy and improving quality of life". However, given a proper understanding of the goals of medical and health care, we think that the benefits of such developments are better thought of in terms of promoting health, preventing disease, deepening our understanding of the causes of disease, developing new forms of treatment, saving lives, curing illnesses, slowing the progress of disease, relieving suffering and disability, and caring for people when they are sick, disabled, frail, or elderly[20].

35. We commend what the Declaration says about human cultures, in particular the recognition that cultural diversity "may not be invoked to contravene fundamental human rights and freedoms".

36. We commend what the Declaration says about the need for "new approaches to social responsibility to ensure that progress in science and technology contributes to justice, equity and to the interest of humanity".

37. We would add to the Preamble a reference to the fact that the disciplined reflection on the ethical issues raised by medicine has a long history in the theological and moral philosophy of the Abrahamic faiths.

Comments on *General Provisions*

38. In general, we endorse the general provisions of the Declaration and in particular its aims.

Comments on *Principles*

39. This section proclaims fifteen ethical principles, which are intended to provide a basis for states to develop legislation; to stimulate reflection, decision making, and teaching; and to guide future consensus regarding bioethical issues that are controversial today. We com-

12. UNESCO, "Draft Universal Declaration on Bioethics and Human Rights".
13. United Nations, Preamble to the "Universal Declaration of Human Rights" (December 10, 1948), http://www.unhchr.ch/udhr/lang/eng.htm.
14. Ibid.
15. See United Nations, Fact Sheet No. 2 (Rev. 1), "The International Bill of Human Rights", http://www.ohchr.org/english/about/publications/docs/fs2.htm.
16. The Human Rights Committee was set up by the United Nations to implement and monitor the International Covenant on Civil and Political Rights.
17. Human Rights Committee, "General Comment 6: The Right to Life" (Sixteenth Session, 1982), Report of the Human Rights Committee, U.N. doc. A/37/40, 93–94, http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/84ab9690ccd81fc7c12563ed0046fae3? Opendocument.
18. United Nations, "International Covenant on Civil and Political Rights" (December 16, 1966), article 4, n. 2, http://www.ohchr.org/english/law/ccpr.htm.
19. Ibid., article 4, n. 1.
20. Catholic Health Australia, *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia* (Canberra, Australia: CHA, 2001), Part 1, Section 3.

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mend much of their content. In particular, the principles contain some powerful intellectual tools for evaluating current market-oriented practices that influence access to, and distribution of, health care.

However, we think these principles should be strengthened in the two ways, which are set out below, in paragraphs 40 and 41.

40. The principles stand in need of a background account of the human values that give them their meaning and significance. Without such a background, it is hard to see how reference to these principles could achieve the Declaration's stated aims. For, on their own, these principles provide insufficient resources to enable correct and reasonable resolution of difficult ethical decisions about the proper treatment and care of people who are very young, very old, frail, unresponsive, cognitively impaired, dying, or otherwise vulnerable. A sound bioethics is one that could provide the values, principles, and guidelines needed to deepen our understanding of the significance of human life and of its moral challenges, resolve difficult questions in the care of those who are very young, elderly, frail, unresponsive, or dying, and properly inform social policies or laws with respect to the care of people in such circumstances. This would include at least (1) an account of the value of human life itself[21]; (2) an account of human flourishing and human decline that is informed by a sense of the preciousness of human life, the significance of giving and receiving love, the mystery of death, and the prohibitions and exhortations found in common morality; (3) an account of medicine's traditional healing ethics – in particular, an account of the contribution of medical intervention to human flourishing in the face of decline and inevitable death, the benefits such intervention can offer, and the burdens it may impose; (4) an account of the responsibilities of those who care for people who are unable to make health-care decisions for themselves; and (5) a clearer account of the concept of distributive justice.

41. The meaning of some of the key terms in the principles is not clear. We suggest the following clarifications:

- While the term *human being* is used in the Preamble and in Article 14 (b), the Declaration elsewhere uses the term *human person*. To avoid confusion, the Declaration should make it clear that the term human person refers to a *living human being*.
- The expression "respect for the *autonomy* of the person" should clearly refer to the capacity of a human being to be responsive to the demands of morality. In this sense, respecting autonomy enjoins recognition of and respect for a human being in virtue of the kind of living being he or she is: that is, a being (a) by nature capable of being self-directed in the conduct of his or her life, and (b) whose capacity for self-direction is properly exercised with a view to the part of his or her flourishing that consists in acting well[22].
- Reference to the *common good* should clearly refer to the protection of those fundamental human values, including the value of human life itself, which are goods for every human individual and therefore goods to be socially protected.

42. In view of these reservations, we conclude that, as they stand, the principles do not yet provide the "universal framework of fundamental principles and procedures to guide States in the formulation of their legislation, policies or other instruments in the field of bioethics" (Article 2 (i)).

Comments on *Application of the Principles*

43. The reservations we have expressed about the principles contained in the Declaration imply correlative reservations about what is said in this section.

44. We endorse the desirability of periodic review of the Declaration.

45. We endorse the promotion of public debate. We include religious as well as cultural and philosophical views among the "relevant" opinions. Contemporary Catholic thinking on bioethical issues encompasses, on the one hand, universal truths (principles, values, virtues, and ideas) which are rationally discernible and held in common with other traditions of thought and, on the other hand, distinctively Christian ideas.

46. We note that, since different types of ethics committees serve different purposes, their composition should reflect the purpose for which they exist. We agree that ethics committees should be pluralist in the following sense: that their members take into account the diversity

21. Life is a fundamental human value. From this value comes the principle that human life ought to be respected, protected, and promoted from its beginning, through all its phases, until its natural end. This value generates traditional morality's prohibitions (e.g., do not kill, do not intentionally harm) as well as its exhortations (e.g., relieve pain and ease suffering, improve individual well-being).

22. In its current form, the first sentence in Article 5 of the Declaration is incoherent.

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of perspectives which, stemming from different religious traditions and belief systems, may inform a richer understanding of moral values and so aid good decision making in ethics. Accordingly, we believe hospitals should have access to ethics committees that have the expertise to provide advice that is informed by the religious as well as the ethical and cultural dimensions of their work; that consultation with clinical ethics committees should be at the invitation of a patient, the patient's representative, or a clinician[23]; that referral of particular cases to clinical ethics committees should respect patient privacy and professional privilege; and that advice given by ethics committees should be in the form of general principles and protocols applicable to like cases.

47. We endorse the Declaration's insistence in Article 21 (b) that, where research is carried out in one country and partially or wholly funded by sources from one or more countries, such research should be subjected to ethical review in all the countries involved.

Comments on *Promotion of the Declaration*

48. The reservations we have expressed about the principles imply correlative reservations about what is said in this section. In particular, our reservations have significant implications for what should be taught and encouraged in any educational program. For example, the Declaration should make reference to the importance of States' promoting education on respecting human life at every stage. The Declaration should note the special care needed to inform the conscience of individuals in cultures in which suffering, nonproductiveness, and death are generally regarded as lacking in meaning. In addition, bioethical programs should clarify the proper relationship between ethics, on the one hand, and public policies, in particular the law, on the other. The law should reflect moral values and requirements as well as provide a safe and procedurally just sphere for individual activity.

Comments on *Final Provisions*

49. The reservations we have expressed about the principles imply correlative reservations about what is said in this section.

Conclusion of the Consensus Statement of the Melbourne Colloquium

50. The under-signed participants in the IACB colloquium in Melbourne agree to the points in this consensus statement, while acknowledging that there are some further questions for continuing study and discussion[24]. They are also committed to living out what has been expressed in this statement in their spheres of activity.

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23. There are a number of Catholic hospitals, particularly in the United States, that are now evaluating proactive ethics consultation services. This was not a topic that was discussed at the colloquium.
24. See especially notes 1, 5, and 6 above.