CATHOLICS UNITED ON BRAIN DEATH AND ORGAN DONATION
A CALL TO ACTION

February 27, 2024

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Abstract

Catholics have long debated whether brain death (BD) represents true death and whether the BD criteria used in clinical practice are adequate to demonstrate "complete and irreversible cessation of all brain activity" (whole BD). The current clinical criteria, as evidenced in scientific studies over the past decade, systematically fail to confirm whole BD. In 2023 the American Academy of Neurology (AAN) issued updated guidelines confirming it does not require complete and irreversible cessation of all brain activity for a BD diagnosis. These guidelines allow patients with continued hypothalamic function to be declared dead, even as this part of the brain continues to function in at least half of patients declared brain-dead. Endorsers of this statement represent a broad range of specialties and—whether they reject whole BD as true death, accept whole BD as true death, or remain undecided about whole BD—all agree that the BD criteria found in the guidelines and used in current clinical practice do not provide moral certainty that a patient has died. Given that the Catholic Church requires moral certainty of death as a condition for removing organs when this would otherwise kill the patient, that the majority of organ donors are declared dead using the existing BD criteria, and that there is no expectation that the guidelines will be revised any time in the near future in such a way as to establish moral certainty of death, the endorsers recommend a number of concrete actions for Catholics in the pew, policy makers, pastors and faith formators, health care professionals and institutions, and Catholic leaders. The recommendations are geared toward the following common goals: (1) protect the lives of vulnerable patients who may be killed by organ procurement; (2) form consciences to enable sound and informed health care decision making at the end of life, including organ donation decisions; (3) develop criteria that will establish moral certainty of death, which may or may not include BD criteria; and (4) protect the consciences of patients, health care professionals, and health care institutions so that no person or institution is forced to accept the use of BD criteria.

Catholics United on Brain Death and Organ Donation: A Call to Action

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***N.B.** The following practices are beyond the scope of this statement: determination of death using circulatory criteria; organ donation after declaration of circulatory death; and any organ donation in which the donor is expected to continue living after organ removal, e.g., a healthy adult donating a single kidney. As such, nothing herein is intended to imply support of or opposition to these practices.*

Introduction and Rationale

The concept of brain death (BD) has been controversial since its introduction in 1968. It claims that death has occurred when the brain no longer functions. According to the 1981 Uniform Determination of Death Act (UDDA), a template law that has been adopted by most states in the United States, a person is legally dead if there is "irreversible cessation of all functions of the entire brain, including the brain stem." Recently a revision was proposed to the UDDA (rUDDA), which sought to change this definition so that persons with some persistent brain function could also be considered legally dead. This would have brought the legal definition of death into alignment with current clinical practice for determining BD.

In response to the rUDDA, several prominent Catholic physicians and bioethicists, including some supporting and some opposing the concept of BD as a matter of principle, wrote a joint letter calling for Catholics to unite against the proposed changes. Their premise was simple: "the current clinical criteria for the determination of brain death…are insufficient in that they simply do not test for whole-brain death. They test for partial brain death." Since the Catholic Church has never accepted partial BD, they all agreed that the UDDA should not be changed to "align the definition of brain death with our current, inadequate clinical criteria." Arguing in similar terms, the United States Conference of Catholic Bishops (USCCB) and The National Catholic Bioethics Center (NCBC) observed that "the clinical guidelines developed by the American Academy of Neurology and others do not assess neuroendocrine function, thus allowing patients with integrated functioning of the hypothalamus to be declared whole brain dead." Thanks to the advocacy of these authors and many others, the rUDDA has been set aside for now.

Shortly after this victory, however, the American Academy of Neurology (AAN) published updated medical guidelines for determining BD. The AAN guidelines are commonly accepted criteria for determinations of BD throughout the United States and are considered the most rigorous and comprehensive, although substandard variations of these criteria are often used in clinical practice. Yet these new guidelines accept the clinical inadequacies inherent in the rUDDA while admitting a "lack of high-quality evidence." As a key example of inadequacy, the guidelines

state that clinicians can declare a person brain-dead despite evidence of persistent function of the hypothalamus, which is a part of the brain. The compatibility of continuing neuroendocrine function (including the hypothalamus) with a determination of BD is not new. It was included in the 1995 AAN adult guidelines, implied (but not explicitly stated) in the 2010 AAN adult guidelines, and adopted as a position of the AAN in 2019. The lead author of the 2023 AAN Guidelines, Dr. David Greer, underscored in a recent interview that the AAN has always considered hypothalamic function compatible with a diagnosis of BD: "loss of neuroendocrine function has never been included in that list [of what is needed to diagnose BD] and still is not included today." Rather than improving the existing criteria, particularly in light of the strong opposition to the rUDDA, the new guidelines have once again affirmed that there need not be complete cessation of all functions of the entire brain to declare a patient brain-dead.

In his 2000 Address to the International Congress of the Transplantation Society, John Paul II made clear that BD could potentially offer moral certainty of death only if there were "complete and irreversible cessation of all brain activity." We recognize that many Catholics supporting the validity and use of the existing BD criteria have been unaware of the frequency of hypothalamic function in patients declared brain-dead. A summary statement of a symposium on BD at The Catholic University of America in 2014—signed by an impressive list of faithful Catholic physicians and intellectuals—concluded with this critical observation expressing uncertainty:

> The question of whether and to what extent hypothalamic function can be preserved in some cases that otherwise meet the current clinical criteria for brain death requires further investigation. If it is established that significant hypothalamic function can be retained, despite rigorous adherence to the current clinical criteria for brain death, this is a matter of grave concern, since this function could potentially mediate some forms of integration.

Evidence published over the past decade demonstrates that as many as 84% of patients declared brain-dead using the AAN guidelines have preserved hypothalamic function as evidenced by absence of central thyroid deficiency, and 50% have persistent hypothalamic function as indicated by absence of central diabetes insipidus. This makes it very clear that the current clinical criteria for determining BD, including the AAN guidelines and less rigorous variations of those guidelines, do not establish complete and irreversible cessation of all functions of the entire brain. Simply put, *the current BD criteria in widespread use do not provide moral (prudential) certainty of death.*

Since the current BD criteria do not provide moral certainty of death, and since it is morally wrong to remove vital organs when this would kill the patient, it is therefore wrong to remove organs from patients declared dead using these inadequate criteria. In his earlier cited address to the transplantation society, John Paul II went on to say that "only where such certainty exists…is it morally right to initiate the technical procedures required for the removal of organs for transplant." Benedict XVI noted in 2008 that "individual vital organs cannot be extracted except *ex cadavere*," specifying that "there cannot be the slightest suspicion of arbitration [arbitrariness] and where certainty has not been attained the principle of precaution must prevail." The principle of precaution means that a patient is presumed alive until death is certain. If death is not certain, vital organs cannot be harvested because that would kill the patient. While the *Catechism of the Catholic Church* teaches that "organ donation after death is a noble and meritorious act," it also affirms that it is "morally inadmissible directly to bring about the disabling mutilation or death of a human being, even in order to delay the death of other persons" (n. 2296).

As Catholics, we have an obligation to defend the sacredness of human life from conception to natural death. Given the facts above, even as there remains disagreement about whether and how the criteria could be improved, *we call on our fellow Catholics to unite against utilization of the current BD criteria, especially when determining death before vital organ transplantation.*

Summary Points of Agreement

In short, we the undersigned agree that:

1. **There is no moral certainty of death when following the AAN guidelines for a determination of BD**. This is clear from the above.

2. **Patients can expect that the existing, inadequate AAN guidelines—or something even less rigorous—will be applied in clinical practice**. Investigations of policies and clinical practice around the United States in 2016 and in 2019 and around the world in 2020 indicate that the existing guidelines are not consistently applied, such that a patient in the exact same clinical state may be alive at one hospital but declared brain-dead at another. The desire to establish uniformity in practice was part of the drive behind the problematic rUDDA effort.

3. **There is no reasonable expectation that the existing guidelines will be revised any time in the near future in such a way as to ensure moral certainty of death**. Those who believe that moral certainty of death can be achieved with better clinical criteria will continue to advocate for such improvement. Nonetheless, the most recent guideline revision came 13 years after the prior version, and that version came 15 years after its predecessor. Neither indicated any intention of changing the position that ongoing hypothalamic function is compatible with BD. Concerns over conflict of interest exist regarding the organ transplantation industry, because organ procurement organizations profit in direct proportion to the number of organs they harvest. Improved clinical guidelines that require cessation of hypothalamic function would immediately reduce the number of donors declared dead using BD criteria by at least half. It would take years of hard work to establish sufficient agreement among all stakeholders, update the guidelines themselves, and then train health care professionals to achieve consistent, widespread change in clinical practice.

4. **A person considering organ donation does not have good reason to expect that he or she will be truly dead at the time of vital organ procurement.** Physicians who personally conduct determinations of death may wish to use more rigorous BD criteria that they are convinced, in conscience, truly establish whole BD. However, no one can know in advance which health care facility or physician will be involved in the determination of his or her death or which criteria will be used. In the United States, 70% of donors were declared dead using BD criteria in 2021. Given that we must presume life in every case until death is certain, and given the lack of moral certainty of death whenever the current BD criteria are used, a clear majority of vital organ donors can be presumed alive at the time of organ harvesting.

Action Recommendations

Therefore, we *strongly recommend* the following initial action steps for all Catholics and all people of good will.

For personal health care decision-making

1. **Decline organ donor status at the Department of Motor Vehicles (DMV) upon first receiving a driver's license, or revoke organ donor status through the appropriate channel in your state**. The process of agreeing to be an organ donor at the DMV does not require or ensure proper informed consent, and as discussed above, there is a significant likelihood of being alive when organs are harvested following a declaration of BD. For those who previously elected to be organ donors on their licenses, simply removing that indication from the driver's license is insufficient. Steps must be taken, varying among states, to ensure you are removed from the organ donor registry (see additional action step below under stakeholders/policy makers section).

2. **Document refusal of organ donation after death in advance directives**. We believe it would be prudent for most people simply to decline consent for organ donation and document this. Those who are familiar with the nuances of determination of death and organ donation may wish to spell out specific conditions under which they would consent to organ donation. This assumes (1) they are convinced in conscience that such conditions would establish moral certainty of death and (2) they have confidence that their wishes will be understood and carried out in practice by their proxy and attending medical professionals when they cannot speak for themselves. According to the 2009 revision of the Uniform Anatomical Gift Act, unless a patient has documented evidence refusing to be an organ donor, authorized persons can make that patient an organ donor. In this circumstance, organ procurement organizations may pressure family or proxy decision makers to consent to donation of a loved one's organs when that person is incapable of providing consent.

3. **Carry a wallet card refusing organ donation**. For those who decide to refuse organ donation, this can be kept with your driver's license. For an example of such a card, see here.

4. **Consider consenting to bone or tissue donation in advance directives**. For those who strongly wish to make a charitable gift of self after death, bone and tissue donations from a cadaver do not rely on the current inadequate BD guidelines. As such, they do not involve the same concerns about causing death by vital organ procurement. Nonetheless, we recommend due diligence in investigating and understanding other ethical and practical issues that can arise with any donation after death. For example, hurried tissue harvesting following death has at times precluded performing autopsies later deemed necessary for medical or legal reasons. The intention of helping others is noble, but consent should not be given without a thorough understanding of the process and all attendant risks.

For all stakeholders and policy makers

1. **Advocate for easy, readily accessible methods to opt out of being an organ donor for those who have previously opted in.** Simply removing the organ donor designation on your driver's license will not remove you from the organ donor registry. Moreover, some states have no information available on the internet for how to be removed from the organ donor registry (despite having abundant information on how to become registered as an organ donor). Transparency, simplicity, and accessibility are needed.

2. **Advocate for the right of patients and health care professionals to conscientiously object to the use of BD criteria for a determination of death.** Laws and policies respecting this right should be implemented at both the state and federal levels. There should be clear and simple accommodations for conscientious objection, including objections to hospital policies on BD. Of particular note, parents should have the right to object to the use of BD criteria for their children.

3. **Advocate for the right of physicians who decline to utilize BD criteria not to be penalized in any way.** This includes (but is not limited to) the loss of employment, hospital credentialing and privileging, state medical board licensing, and specialty maintenance of certification. The AAN has advocated that physicians who determine BD be credentialed through training programs which adhere to the AAN guidelines, a process which could become mandatory. Physicians should have the right to conscientiously object both to utilization of and training in BD criteria, without fear of penalty.

4. **Advocate for the right of patients and their proxies to be informed and to provide consent prior to BD determinations.** The 2019 AAN position statement and the 2023 AAN guideline update acknowledge that the apnea test (part of the BD evaluation) can harm the patient. At the same time, they assert that informed consent is not required prior to BD testing. Yet patients and their proxies have a clear right to informed consent before any test or procedure that may cause harm. Furthermore, given the principled philosophical and religious convictions of many that BD does not represent true death, the ongoing debates and questions surrounding BD not only among experts but also in the public square, the fact that the current clinical criteria for BD only test for partial BD, and the inconsistent application of those inadequate BD criteria, no BD evaluation should be conducted unless consent has been obtained.

5. **Advocate for clarification of government regulations and accreditation standards, with amendment if necessary, to ensure that hospitals and health care systems will not be penalized for declining to utilize BD criteria.** Health care organizations and their medical staff that either use a higher bar for declaring BD (which would include additional criteria beyond the AAN guidelines) or decline to use BD criteria altogether should not lose accreditation by The Joint Commission or its global equivalent, Det Norske Veritas (DNV), because of this. The Conditions of Participation of the Centers for Medicare and Medicaid Services (CMS), which shape the standards of The Joint Commission and DNV and enable a health care organization to participate in and receive federal payment from Medicare or Medicaid programs, should neither require hospitals to use BD guidelines for declaring death nor require them to participate in organ transplantation involving donors

declared dead based on those criteria. We should advocate for collaboration between all stakeholders, including medical staff, the Centers for Medicare & Medicaid Services, The Joint Commission, DNV, and the Health Resources & Services Administration, to help achieve this goal.

6. **Advocate for more rigorous BD criteria.** Those not opposed to BD in principle should continue to advocate for the AAN to develop more rigorous BD criteria, based on high-quality evidence, that would establish whole BD instead of partial BD.

7. **Advocate for greater private and public funding of research and development of alternative medical and surgical options for organ transplantation candidates that are both highly effective and ethically sound.** "I express the hope that, thanks to the work of so many generous and highly-trained people, scientific and technological research in the field of transplants will continue to progress, and extend to *experimentation with new therapies which can replace organ transplants.*" (John Paul II, Address to the Transplantation Society, 2000)

For Catholics engaged in faith formation and pastoral guidance

1. **Firmly reiterate the Church's teaching on the need for moral certainty of death as a condition for vital organ procurement.** The Church's teaching on the legitimacy of organ donation after death as a generous gift of self *requires* the assurance that vital organs will be procured from a cadaver ("*ex cadavere*"). Certainty of death is an indispensable condition for moral legitimacy of vital organ procurement. Secular bioethics has long recognized this in the "dead donor rule."

2. **Provide the facts and ethical considerations mentioned in this statement and additional resources on BD and organ transplantation.** This will facilitate Catholics in making a well-informed decision about whether to donate and/or receive organs procured after a declaration of death. At a minimum, Catholics should know that: (1) vital organ donation, while a noble and generous act in principle, becomes immoral in practice when there is no moral certainty of death; (2) while there is disagreement among Catholics about whether whole BD represents true death, all Catholics agree partial BD does not; (3) the current medical guidelines for BD cannot provide moral certainty of death because they only test for partial BD; and (4) the average person cannot expect to be dead at the time of organ harvesting because the majority of organ procurements rely on inadequate BD criteria.

3. **Firmly reiterate the Church's teaching on the legitimacy of declining or withdrawing extraordinary means of preserving life.** Some people worry that, without a declaration of BD, comatose patients must be kept alive indefinitely on a ventilator. This is an unfounded fear. A declaration of BD is *not* necessary for a patient (or patient's proxy) to decline extraordinary means (i.e., interventions that in the patient's judgment, after a careful evaluation of the concrete circumstances and in light of Catholic moral principles, do not provide a reasonable hope of benefit or that entail excessive burden or cost). While the Catholic moral tradition requires the provision of basic human care to all patients, it

has always permitted a patient to refuse disproportionate means, which can include ventilators, even when it is foreseen that the patient's death will result.

For health care professionals

1. **Decline making declarations of death using the current BD criteria.** As stated above, the AAN guidelines and anything less rigorous test only for partial BD, and therefore cannot provide moral certainty of death. Health care professionals who are convinced of the validity of BD in principle and *do* wish to make determinations of death using BD criteria should do so based on *more rigorous* standards than the current guidelines, such that in conscience they can be morally certain of the complete and irreversible cessation of all functions of the entire brain. Greater rigor includes addressing concerns about patient safety, specifically during the apnea test, but that is beyond the scope of this statement. We strongly recommend that health care professionals inform themselves on this topic to be able to reach sound medical-moral judgments.

2. **Conscientiously object to involvement with organ procurement following declarations of death using the current BD criteria.** For simplicity, clarity, and witness against widespread organ harvesting practices that actually cause the donor's death, and while ongoing discussion continues about which BD criteria (if any) *could* provide moral certainty of death, we recommend objecting to any involvement with organ procurement following declarations of death using the current BD criteria. While subjective culpability may vary based on understanding and intent, those who routinely procure organs after BD declarations using inadequate criteria are directly involved in killing patients. This does not rule out the possibility that some health care professionals might participate in organ procurements based on the firm conviction, in conscience, that moral certainty of death was established by more rigorous criteria.

For health care institutions

1. **Establish policies and protocols that uniformly hold clinicians to a higher bar for declarations of death.** We recommend *ceasing the use of current BD criteria altogether* while working with medical staff and ethicists to identify which, if any, BD criteria would provide moral certainty of death. Any policies allowing the use of BD criteria should include specific additional requirements beyond the current AAN guidelines that system leadership is convinced, in conscience, will establish whole BD. Such policies and protocols should also account for concerns about patient safety during apnea testing.

2. **Renegotiate agreements with organ procurement organizations, if necessary, to ensure respect for institutional policies and protocols around declarations of death**. If they cannot be renegotiated, consider shutting down deceased donor organ transplantation programs and ending these agreements altogether.

3. **Educate staff and patients about ethically legitimate refusals of extraordinary measures and physicians' conscience rights.** Patients and their proxies may decline ventilator support when the burdens outweigh the benefits. Physicians are not obligated to participate in interventions that are contrary to their own conscience judgments.

For individual and organizational Catholic leaders

1. **Update model advance directive documents and guidance to protect patients from organ procurements that violate Catholic teaching**. State Catholic conferences of bishops, as well as lawyers, health care organizations, bioethics groups, and others, should ensure that their end-of-life guidance and forms adequately address (1) Church teaching on the need for moral certainty of death and the principle of precaution (i.e., a person must be presumed alive in cases of uncertainty); (2) the lack of that certainty in the majority of organ donations following a declaration of death; and (3) the moral implications for decisions about organ donation.

2. **Update the *Ethical and Religious Directives for Catholic Health Care Services* to address the role of moral certainty in the determination of death**. This important guidance from the United States Conference of Catholic Bishops states that death should be determined "in accordance with responsible and commonly accepted scientific criteria" (n. 62) and that "organs should not be removed until it has been medically determined that the patient has died" (n. 64). This language is not sufficiently clear to address the matter of moral certainty. Updated language should help Catholic health care professionals, ethicists, and leaders to assess whether medical determinations and scientific criteria are ethically responsible, regardless of whether they happen to be commonly accepted.

3. **Coordinate and engage in further collaborative research, discussion, and action**. Recognizing the importance of the principle of precaution when determining death before organ procurement, stakeholders in health care practice, health care ethics, academia, law, and public policy should join together "to promote research and interdisciplinary reflection to place public opinion before the most transparent truth on the anthropological, social, ethical and juridical implications of the practice of transplantation" (Benedict XVI, Address at an International Conference Organized by the Pontifical Academy for Life, 2008). Such efforts should also address related ethical issues such as the risks of the apnea test, the criteria for declaring circulatory death, protocols for donation after circulatory death, emerging practices such as normothermic regional perfusion with controlled donation after circulatory death, and the numerous ethical concerns surrounding organ transplantation after death, including conflicts of interest, organ procurement organization pressure and influence, financial incentives for increasing organ retrievals and transplants, and more.

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This statement was prepared by Joseph M. Eble, MD, John A. Di Camillo, PhD, BeL, and Peter J. Colosi, PhD. Endorsements by individuals and organizations are listed below.

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