THE NATIONAL CATHOLIC BIOETHICS CENTER
600 REED ROAD, SUITE 102, BROOMALL, PA 19008 (215) 877-2660 (215) 877-2688 FAX NCBCENTER.ORG

Integrity in the Determination of Brain Death: Recent Challenges and Next Steps

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ABSTRACT

The failure of recent efforts to resolve an important dispute regarding the determination of brain death instead revealed a decisive breakdown in the public consensus on death and organ donation. This breakdown has profound implications for the entire field of organ transplantation, from organ donors and recipients to everyone playing a role in this important endeavor. Catholic health care institutions and professionals should act to help resolve the critical issues and questions at stake.

Key Recent Events

Events in the last several months have revealed a decisive breakdown in a shared understanding of brain death (death by neurological criteria) which has been critical in shaping the ethical practice of organ transplantation. At stake now is whether clinicians, potential organ donors, and society can agree on what it means to be dead before vital organs are procured.

First, on September 22, 2023, an effort to revise the 1981 Uniform Determination of Death Act (UDDA) by the Uniform Law Commission was paused indefinitely after an impasse was reached in July.[1] The UDDA provides a widely accepted legal framework enabling states to have consistent laws on how to determine death, particularly brain death. While many revisions were considered, several proved to be quite controversial. The most controversial proposal, which will be the focus of this statement, was advanced after public acknowledgment that the most influential clinical guidelines for diagnosing brain death were not consistent with the text of the UDDA itself.[2] The UDDA defines brain death as the "irreversible cessation of *all functions*

[1]See Uniform Law Commission, "Welcome, Background, Committee Charge, Committee Overview, Scheduling and Reference Materials," September 23, 2021; "Final Report and Recommendation (June 16, 2021)"; and Kate Robinson, "UCL 2023 Annual Meeting Highlights," Uniform Law Commission (August 2, 2023). See also Robert D. Truog, MD, and David C. Magnus, "The Unsuccessful Effort to Revise the Uniform Determination of Death Act," *Journal of the American Medical Association* 330.24 (2023): 2335–2336, doi: 10.1001/jama.2023.24475.

[2] Adam Omelianchuck et al., "Revise the Uniform Determination of Death Act to Align the Law with Practice through Neurorespiratory Criteria," *Neurology* 98.13 (March 29, 2022): 533, doi: 10.1212/WNL.0000000000200024; and A. Lewis, R. Bonnie, and T. Pope, "It's Time to Revise the Uniform

of the entire brain, including the brain stem (emphasis added)."[3] Yet, despite evidence that some parts of the brain—primarily the hypothalamus, a part of the neuroendocrine system—continue to function in roughly half of patients who might otherwise qualify as brain dead,[4] clinical guidelines did not require testing for neuroendocrine function (NEF) before diagnosing brain death.[5] To resolve this significant inconsistency, some organizations and clinicians proposed to change the UDDA's standard of whole brain death ("all functions of the entire brain") to partial brain death,[6] to bring the revised UDDA into alignment with current clinical guidelines. However, agreement on this and other controversial proposals could not be reached and so the effort to revise the UDDA was paused indefinitely.

Second, on October 11, 2023, the American Academy of Neurology (AAN), together with the American Academy of Pediatrics, the Child Neurology Society, and the Society of Critical Care Medicine (the "AAN et al."), published updated guidelines for diagnosing brain death (2023 AAN Guidelines).[7] Of note, the AAN et al. were aware of the inconsistency noted above and had supported changing the UDDA's brain death standard to make it align with their own guidelines. But after the effort to revise the UDDA was paused, the AAN et al. did not reconsider their stance on testing for neuroendocrine function. Rather, less than three weeks later, the AAN et al. issued new guidelines stating more explicitly than ever that clinicians may declare patients brain dead *despite evidence of neuroendocrine function*.[8]

Clinical, Ethical, and Public Policy Issues

The issue of neuroendocrine function is significant and the action of AAN et al. is profoundly troubling. First, it is important to appreciate the nature and function of the hypothalamus. The hypothalamus can be understood as a kind of "smart" coordinating center in the brain which is involved in regulating temperature, salt-water balance, sex drive, and

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Determination of Death Act," *Annals of Internal Medicine* 172.2 (January 2020): 143–145, doi: 10.7326/M19-2731.

[3] National Conference of Commissioners on Unform State Laws, *Uniform Determination of Death Act* (August 1, 1980), §1.

[4] M. Nair-Collins and A.R. Joffe, "Hypothalamic function in patients diagnosed as brain dead and its practical consequences," *Handbook of Clinical Neurology* 182 *(*2021): 433–446.

[5] M. Nair-Collins, "Must hypothalamic neurosecretory function cease for brain death determination? Yes," UDDA Revision Series, *Neurology* 101.3 (July 18, 2023): 134–136, doi: 10.1212/WNL.0000000000207340.

[6] See Draft for Uniform Determination of Death Act (20), June 28, 2023, at 2.

[7] David M. Greer et al., "Pediatric and Adult Brain Death/Death by Neurologic Criteria Consensus Guideline: Report of the AAN Guidelines Subcommittee, AAP, CNS, and SCCM," *Neurology* 101 (2023): 1–21, doi: 10.1212/WNL.0000000000207740.

[8] Greer et al., "Pediatric and Adult Brain Death," *Neurology*: 17. "Clinicians may initiate a BD/DNC evaluation and determine a patient BD/DNC despite evidence of neuroendocrine function (Level B)." This is a more explicit statement than in past AAN guidelines.

sleep.[9] Recent studies show that it may play a role in phenomenal awareness and pain detection.[10] Hypothalamic functioning shows that *not all functions of the entire brain* have ceased, as stipulated by the UDDA. Consequently, patients with confirmed hypothalamic function should not be diagnosed as brain dead, nor treated as dead, for the purpose of organ procurement.[11]

There have been questions and tensions surrounding the concept and determination of brain death for decades.[12] In the context of academic articles, some have blatantly admitted that individuals pronounced dead by neurological criteria are not really dead.[13] Others have pointed out multiple ambiguities inherent in brain death standards and then called for new standards that would permit taking vital organs from patients who are profoundly brain injured but not brain dead.[14] However, the recent actions of the AAN et al.— important institutions whose guidelines are highly influential—represent a formal breach in a longstanding consensus in law and public policy.

The AAN et al. acknowledged a clear conflict between the law and public policy, on the one hand, and their clinical guidelines and practice on the other, when they supported revision of the UDDA. And yet, rather than resolve this conflict in open dialogue with other experts and interested parties, the AAN et al. adopted as new guidelines some of the very proposals they could not convince the Uniform Law Commission to approve. These issues should be of profound concern to Catholics, in particular to Catholic health care institutions and professionals.

The Catholic Church has long encouraged organ transplantation if it respects three ethical principles: (1) the organ donor must be truly dead before vital organs may be taken; the act of organ procurement must not kill the donor; (2) there must be free and informed consent;

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[9] H. Blumenfeld, "Pituitary and Hypothalamus," in *Neuroanatomy through Clinical Cases* (Sunderland: Sinauer Associates, 2002), 736–759.

[10] A. May, A. Bahra, C. Büchel, R.S.J. Frackowiak, and P.J. Goadsby, "Hypothalamic activation in cluster headache attacks," *Lancet* 352.9124 (1998): 275–278, doi: 10.1016/S0140-6736(98)02470-2; and James Giordano and Joan Engebretson, "Neural and cognitive basis of spiritual experience: biopsychosocial and ethical implications for clinical medicine," *EXPLORE* 2.3 (May 2006): 216–225, doi: 10.1016/j.explore.2006.02.002.

[11] D.P. Sulmasy, C.A. DeCock, "Rethinking brain death—why 'dead enough' is not good enough," UDDA Revision Series, *Neurology* 101 (2023): 320–325, doi: 10.1212/WNL.0000000000207407.

[12] For example, in 2008, the President's Council on Bioethics reviewed challenges to theories and protocols regarding brain death and recommended a major change in how brain death should be understood. President's Council on Bioethics, *Controversies in the Determination of Death* (Washington, D.C. 2008).

[13] Robert M. Sade, MD, "Brain Death, Cardiac Death, and the Dead Donor Rule," *JSC Medical Association* 107.4 (August 2011): 146–149.

[14] Robert D. Truog, MD, and Franklin G. Miller, "The Dead Donor Rule and Organ Transplantation," *New England Journal of Medicine* 359.7 (August 14, 2008): 674–675.

and (3) the act of donation must be a true gift, not a commercial transaction. For example, in his encyclical, *Evangelium vitae*, Pope St. John Paul II described organ donation as "a particularly praiseworthy example" of "everyday heroism" that offers "a chance of health and even of life itself to the sick who sometimes have no other hope." However, he stated that this life-affirming act must be "performed in an ethically acceptable manner."[15] Moreover, popes have addressed the concept of brain death. In 2000, Pope St. John Paul II taught that "*complete and irreversible* cessation of all brain activity, if rigorously applied, does not seem to conflict with the essential elements of a sound anthropology." (emphasis in original).[16] In 2008, Pope Benedict XVI stipulated that, ". . . there cannot be the slightest suspicion of arbitration [arbitrariness] and where certainty [of death] has not been attained the principle of precaution must prevail . . . the principal criteria of respect for the life of the donator must always prevail so that the extraction of organs be performed only in the case of his/her true death."[17]

Singer and Camosy have called for a public debate on the issues at hand.[18] Catholics should participate in this debate. But beyond debating, Catholics have a responsibility to bring the full resources of our faith to bear on analyzing and resolving the critical issues at hand.

Action Steps to Address Critical Issues

Bringing the full resources of our faith to bear demands addressing at least three key tasks. First, Catholics must restate and explain better a clear, philosophically coherent concept of death that is compatible with Catholic teachings and rigorous, consistent clinical testing. A whole brain death standard has appeared to be compatible with Catholic teachings. A partial brain death standard can never be acceptable to Catholics. Accepting a partial brain death standard would mean that living patients could be killed (by the removal of their vital organs) to save the lives of others. This would be a gross violation of the sanctity of human life and of the profession of medicine. A partial brain death standard for organ procurement also would be much more likely to be expanded to include other vulnerable patients who are profoundly brain injured but not brain dead. Fortunately, many others in medicine and society reject a partial brain death standard and its implications. For example, the American College of Physicians, the largest medical specialty organization and the second-largest physician membership society in the United States, opposed changing the UDDA's standard of brain death.[19] And a broad

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[15] *Evangelium vitae*, n. 86.
[16] Pope John Paul II, Address to the 18th International Congress on Transplants (August 29, 2000) in *The National Catholic Bioethics Quarterly*, 1.1 (Spring 2001), 89-–92.
[17] Pope Benedict XVI, Address to Participants at an International Congress Organized by the Pontifical Academy for Life, November 7, 2008.
[18] Peter Singer and Charles Camosy, "When Do We Die?," Project Syndicate (November 1, 2023).
[19] Jan K. Carney, MD, Letter to the Uniform Law Commission (June 7, 2023).

societal consensus to ensure that organ donors are truly dead has prevailed for many years in the form of the "Dead Donor Rule."[20] Catholics should work with all people of good will to uphold the sanctity of life of each person and to oppose the validation of any partial brain death standard.

Second, Catholics must reaffirm and strengthen ethical standards and protocols for the determination of death. With regard to ethical standards, we must help to articulate and properly integrate the many goods and demands inherent in post-mortem organ donation. Sometimes the goods at stake, such as increasing the supply of organs, improving success rates, and maintaining public trust, can appear to be in competition. To resolve any conflicts, it is essential to first protect the most important goods and then to promote all others in proper balance. The ultimate good that must be respected is the sanctity of each human life. Both Church teachings and the Dead Donor Rule appropriately stipulate that patients must be dead before, and may not be killed in the course of, harvesting vital organs. Neither the benefits to society of contemporary organ transplantation, nor the clinical, technological, and organizational demands of transplantation programs, may supersede the respect due to every human individual's life. As *Gaudium et Spes* teaches, "The order of things must be subordinate to the order of persons, and not the other way around."[21] Closely related to respecting the sanctity of human life is the need to obtain and respect informed consent.[22]

Historically, protocols for determining brain death have required testing for a specific set of functions: "(a) the capacity for consciousness, (b), the ability to breathe spontaneously, and (c) brainstem reflexes."[23] Although the absence of these functions can be an indicator of death in many circumstances, they are not always sufficient to establish, with moral certitude, that death has occurred, particularly when stable neuroendocrine function appears to be present. Just as a partial brain death standard cannot be acceptable—ethically or legally, so too

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[20] J. Robertson, "The Dead Donor Rule," *Hastings Center Report* 29.6 (1999): 6–14. See also A.L. Dalle Ave, D.P. Sulmasy, and J.L. Bernat, "The ethical obligation of the dead donor rule," *Medicine, Health Care and Philosophy* 23 (2020): 43–50, doi: 10.1007/s11019-019-09904-8.

[21] *Gaudium et Spes*, 26, n. 3 https://www.vatican.va/archive/hist_councils/ii_vatican_council/documents/vat-ii_const_19651207_gaudium-et-spes_en.html.

[22] There have been ongoing disputes about whether or not informed consent is required to initiate testing for brain death, in particular apnea testing. The UDDA does not address this issue. The AAN and others proposed changing the UDDA to state that informed consent is not required to initiate tests for brain death. Even though the revision process failed, the 2023 AAN Guidelines now strongly assert the desired standard that clinicians do not need to obtain consent before an evaluation for BD/DNC unless stipulated by state law or organization policy. This issue must be resolved as well.

[23] A Quality Standards Subcommittee of the American Academy of Neurology, "Practice parameters for determining brain death in adults," Summary Statement, *Neurology* 45.5 (May 1995): 1012–1014, doi: 10.1212/wnl.45.5.1012; and "Evidence-based guideline update: Determining brain death in adults; Report of the Quality Standards Subcommittee of the American Academy of Neurology," *Neurology* 74 (2010): 1911–1918.

any testing regimen that arbitrarily ignores certain brain functions is also unacceptable. What constitutes sufficient testing, and how to appropriately implement this testing in patient-specific cases, remains to be determined.

Third, it is important to educate clinical and administrative leaders about the significant breakdown in a shared understanding of brain death revealed by the recent events described at the beginning of this statement and the impact this breakdown could have—on the lives of patients, on the ethical integrity of Catholic health care institutions and professionals, as well as on the common good. It will be important to educate a broad set of people, including organ donors (current and potential) families, clergy, and the public, about the authentic ethical principles that should govern organ transplantation and which stances and practices fall short of these.

Completing the tasks outlined above will require timely action, focused attention, and the collaboration of individuals and institutions with the requisite expertise. Beyond ensuring that the deaths of potential candidates for organ donation are determined with rigor and consistency, it will be important to examine how strengthened ethical standards and testing protocols will intersect with governmental regulations, clinical standards, and the significant financial reimbursements related to organ transplantation. This will not be easy. Yet, we cannot ignore or shrink from these tasks.

The events of the last several months have revealed a significant breakdown in a shared understanding of brain death, especially in relation to organ transplantation. It is critical that this breakdown does not pass without remark and appropriate response. The NCBC pledges to work with its members, partners, and all others of good will to resolve the issues at hand.