

---

**Neurology Publish Ahead of Print**

**DOI: 10.1212/WNL.0000000000207333**

**[UDDA Revision Series] Should the Brain Death Exam With Apnea Test Require  
Surrogate Informed Consent? No: The UDDA Revision Series**

**Author(s):**

David Greer, MD<sup>1</sup>

**Corresponding Author:**

David Greer, dgreer@bu.edu

**Affiliation Information for All Authors:** 1. Department of Neurology, Boston University School of Medicine and Boston Medical Center, Boston, MA

**Equal Author Contribution:**

**Contributions:**

David Greer: Drafting/revision of the manuscript for content, including medical writing for content

**Figure Count:**0

**Table Count:**0

**Search Terms:**

[ 18 ] Coma, [ 295 ] Critical care, [ 84 ] All Ethics in Neurology/Legal issues, [ 85 ] Brain death

**Acknowledgment:**

**Study Funding:**

The authors report no targeted funding.

**Disclosure:**

The author reports no relevant disclosures.

**Preprint DOI:**

**Received Date:**

2022-09-07

**Accepted Date:**

2023-03-07

**Handling Editor Statement:**

Submitted and externally peer reviewed. The handling editor was Editor-in-Chief José Merino, MD, MPhil, FAAN.

When a patient is admitted to a hospital for treatment, it is general policy and practice that the patient (or their surrogate, if the patient is incapacitated) consents to be treated. Of course, this is not a blanket or all-encompassing consent, and any diagnostic work up or treatment that may pose a risk to the patient necessitates a separate “informed” consent, in which the risks and benefits are explained to the patient or their surrogate, and a decision can be made to proceed with, or decline, such treatment. In general, informed consent is obtained when there is 1) medical risk and 2) a diagnostic work up or treatment that is beyond the norm. For example, a simple venipuncture for laboratory studies does not generally require informed consent, as it is considered part of standard care; however, placement of a central venous catheter generally does require consent, as it carries greater risk and is beyond the “basics” of standard care.

The diagnosis of death by neurologic criteria (DNC), or “brain death” (BD), does not satisfy either of these basic requirements – medical risk or diagnosis/treatment beyond the norm. The primary argument used to justify the need for consent prior to BD/DNC testing is that there is risk to the patient – that a patient who is not brain dead prior to testing could be harmed by the testing itself.<sup>1,2</sup> Specifically, take as an example a patient who has suffered a neurological catastrophe (a requirement prior to *any* consideration of BD/DNC testing) from a massive intracerebral hemorrhage. The patient undergoes standard neurological examinations at the bedside (for which specific consent is never obtained, nor is it required), including detailed cranial nerve testing and assessment for response to noxious stimulation on the cranium, torso and extremities. No signs of brain function, including brainstem function, are noted. The patient then undergoes apnea testing, and carbon dioxide levels are allowed to rise to a level that should be sufficient to stimulate respiration, if the medulla were still functional. However, this rise in carbon dioxide levels can increase cerebral blood flow due to vasodilation, thereby increasing intracranial pressure, worsening the intracranial condition and causing a patient who may not have been brain dead to then become brain dead. That is the argument<sup>3</sup>.

What risk did this pose to the patient? By definition, a patient undergoing BD/DNC testing has suffered a neurological catastrophe. They are comatose and thus cannot experience pain or discomfort. The pre-test probability of BD/DNC should be extremely high prior to apnea testing – one should not be “checking” to see if the patient might be brain dead by chance, but rather, all data should point toward a high likelihood of brain death, particularly their neuroimaging.

The patient's prognosis for recovery should *never* be in question when brain death determination is being entertained. By definition, there is no possibility for recovery - any recovery - of brain function. The argument that a patient could be harmed by brain death determination is thus inherently flawed.<sup>4</sup>

Furthermore, brain death testing is not beyond the norm of intensive care and neurological practice, nor has it been at any time in the last 60 years. Consent has not been required for neurological testing of the brainstem, including the apnea test to assess lower brainstem function, and this is law in all 50 states and delineated in the Uniform Determination of Death Act (UDDA), in which determination of death is made according to "acceptable medical standards."<sup>5</sup> These medical standards have included the 2010 American Academy of Neurology's Practice Parameters in the US for adults<sup>6</sup>, the 2011 American Academy of Pediatrics and Society of Critical Care Medicine standard in the US for children<sup>7</sup>, and the more recent 2020 World Brain Death Project<sup>8</sup>, which evaluated all brain death practicing countries and found *none* that required consent prior to brain death determination.<sup>9</sup>

One cannot choose, nor can their surrogates, whether they are alive or dead. These are legal definitions of death that have been codified into national and state law. There can be no negotiated standard for death, no slippery slope to its determination. Just as with the cardio-respiratory definition of death, where the determination is made meticulously based on clinical examination and time from the heart's cessation, the neurological determination of death requires detailed and thorough examination to ensure total loss of brain function, as well as sufficient time and certainty to the patient's state to ensure permanency. It is incumbent upon clinicians to be entirely accurate with either determination of death, cardiopulmonary or BD/DNC, in order to maintain the public's trust in the process and finality of the diagnosis.

Those who would criticize the safety of the apnea test fail to recognize that the protocol for apnea testing requires that it be done last, after ensuring a catastrophic brain injury consistent with brain death, excluding any potential confounders, finding no other evidence of brain function whatsoever, and meticulously ensuring systemic stability. Avoidance of hypoxia is required throughout the test (hypoxia is not the stimulus to breathe), and clear stopping rules are in place in case the blood pressure or oxygenation drop to unacceptable levels. If a patient cannot safely undergo BD/DNC testing, ancillary testing may be required to ensure systemic stability. When protocols are followed and experienced, multidisciplinary personnel are involved, apnea testing is safe and complications are rare.<sup>4</sup> The pretest probability of apnea prior to testing must be extremely high - meaning a high likelihood that the patient is indeed brain dead. This patient cannot be "harmed" in any meaning of the word.

We do not consent for death determination by cardiorespiratory criteria. We do not stop performing CPR on a patient in cardiac arrest only when the family agrees to stop. Death determination by brain criteria is no different. A family cannot dictate that their loved one is alive and disallow brain death determination, or any aspect of testing, just because they don't want to accept that their loved one is dead. Brain death is law in all 50 states, and the UDDA has been in effect for > 40 years. The question of the legality of death determination by brain

criteria has been asked and answered by the courts.<sup>10</sup> Both the American Academy of Neurology and World Brain Death Project state specifically that consent is not required. Just as we respect the autonomy of the living and always aim to honor their wishes, we should respect the dignity of the dead and put to rest the issue of consent for any aspect of brain death determination.<sup>11</sup>

## References

1. Shewmon DA. POINT: Whether Informed Consent Should Be Obtained for Apnea Testing in the Determination of Death by Neurologic Criteria? Yes. *Chest*. May 2022;161(5):1143-1145. doi:10.1016/j.chest.2021.11.026
2. Truog RD, Tasker RC. Rebuttal From Drs Truog and Tasker. *Chest*. Oct 2017;152(4):705-706. doi:10.1016/j.chest.2017.05.033
3. Busl KM, Lewis A, Varelas PN. Apnea Testing for the Determination of Brain Death: A Systematic Scoping Review. *Neurocrit Care*. Apr 2021;34(2):608-620. doi:10.1007/s12028-020-01015-0
4. Lewis A, Greer D. POINT: Should Informed Consent Be Required for Apnea Testing in Patients With Suspected Brain Death? No. *Chest*. Oct 2017;152(4):700-702. doi:10.1016/j.chest.2017.05.030
5. Defining Death: Medical, Legal and Ethical Issues in the Determination of Death. Washington D.C.; 1981.
6. Wijdicks EF, Varelas PN, Gronseth GS, Greer DM. Evidence-based guideline update: determining brain death in adults: report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*. Jun 8 2010;74(23):1911-8. doi:10.1212/WNL.0b013e3181e242a8
7. Nakagawa TA, Ashwal S, Mathur M, et al. Guidelines for the determination of brain death in infants and children: an update of the 1987 Task Force recommendations. *Crit Care Med*. Sep 2011;39(9):2139-55. doi:10.1097/CCM.0b013e31821f0d4f
8. Greer DM, Shemie SD, Lewis A, et al. Determination of Brain Death/Death by Neurologic Criteria: The World Brain Death Project. *Jama*. Sep 15 2020;324(11):1078-1097. doi:10.1001/jama.2020.11586
9. Lewis A, Bakkar A, Kreiger-Benson E, et al. Determination of death by neurologic criteria around the world. *Neurology*. Jul 21 2020;95(3):e299-e309. doi:10.1212/wnl.0000000000009888
10. Pope TM. COUNTERPOINT: Whether Informed Consent Should Be Obtained for Apnea Testing in the Determination of Death by Neurologic Criteria? No. *Chest*. May 2022;161(5):1145-1147. doi:10.1016/j.chest.2021.11.029
11. Russell JA, Epstein LG, Greer DM, Kirschen M, Rubin MA, Lewis A. Brain death, the determination of brain death, and member guidance for brain death accommodation requests: AAN position statement. *Neurology*. Jan 2 2019;doi:10.1212/wnl.0000000000006750

# Neurology®

## [UDDA Revision Series] Should the Brain Death Exam With Apnea Test Require Surrogate Informed Consent? No: The UDDA Revision Series

David Greer

*Neurology* published online July 10, 2023

DOI 10.1212/WNL.0000000000207333

**This information is current as of July 10, 2023**

<b>Updated Information &amp; Services</b>	including high resolution figures, can be found at: <a href="http://n.neurology.org/content/early/2023/07/10/WNL.0000000000207333.citation.full">http://n.neurology.org/content/early/2023/07/10/WNL.0000000000207333.citation.full</a>
<b>Subspecialty Collections</b>	This article, along with others on similar topics, appears in the following collection(s): <b>All Ethics in Neurology/Legal issues</b> <a href="http://n.neurology.org/cgi/collection/all_ethics_in_neurology_legal_issues">http://n.neurology.org/cgi/collection/all_ethics_in_neurology_legal_issues</a> <b>Brain death</b> <a href="http://n.neurology.org/cgi/collection/brain_death">http://n.neurology.org/cgi/collection/brain_death</a> <b>Coma</b> <a href="http://n.neurology.org/cgi/collection/coma">http://n.neurology.org/cgi/collection/coma</a> <b>Critical care</b> <a href="http://n.neurology.org/cgi/collection/critical_care">http://n.neurology.org/cgi/collection/critical_care</a>
<b>Permissions &amp; Licensing</b>	Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at: <a href="http://www.neurology.org/about/about_the_journal#permissions">http://www.neurology.org/about/about_the_journal#permissions</a>
<b>Reprints</b>	Information about ordering reprints can be found online: <a href="http://n.neurology.org/subscribers/advertise">http://n.neurology.org/subscribers/advertise</a>

*Neurology*® is the official journal of the American Academy of Neurology. Published continuously since 1951, it is now a weekly with 48 issues per year. Copyright © 2023 American Academy of Neurology. All rights reserved. Print ISSN: 0028-3878. Online ISSN: 1526-632X.

