

# Revise the Uniform Determination of Death Act to Align the Law With Practice Through Neurorespiratory Criteria

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## Abstract

Although the Uniform Determination of Death Act (UDDA) has served as a model statute for 40 years, there is a growing recognition that the law must be updated. One issue being considered by the Uniform Law Commission's Drafting Committee to revise the UDDA is whether the text "all functions of the entire brain, including the brainstem" should be changed. Some argue that the absence of diabetes insipidus indicates that some brain functioning continues in many individuals who otherwise meet the "accepted medical standards" like the American Academy of Neurology's. The concern is that the legal criteria and the medical standards used to determine death by neurologic criteria are not aligned. We argue for the revision of the UDDA to more accurately specify legal criteria that align with the medical standards: brain injury leading to permanent loss of the capacity for consciousness, the ability to breathe spontaneously, and brainstem reflexes. We term these criteria neurorespiratory criteria and show that they are well-supported in the literature for physiologic and social reasons justifying their use in the law.

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## Introduction

At the end of the 1970s, neurologic criteria for death were recognized in roughly half of the United States, resulting in a confusing legal landscape. To achieve uniformity across state lines and alignment of the law with medical practice, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavior Research recommended state legislators adopt the Uniform Determination of Death Act (UDDA)<sup>1</sup>:

An individual who has sustained either irreversible cessation of circulatory and respiratory functions or irreversible cessation of all functions of the entire brain, including the brainstem, is dead. A determination of death must be made in accordance with accepted medical standards.

Although it has served as a model statute for 40 years, and has been embraced in whole or in part throughout the United States,<sup>2</sup> there is a growing recognition that the UDDA must be updated.<sup>3-5</sup> The Uniform Law Commission recently approved a Study Committee's recommendation to form a Drafting Committee that should submit its proposed UDDA revisions by July 2023. Meanwhile, Nevada, Oklahoma, and Texas have already moved to amend their own UDDA statutes (NV. A.B. 424 [2017], Okla. H.B. 1896 [2021], Tex. H.B. 4,329 [2021]). Contentious aspects of the UDDA include interpretation of the phrases "all functions of the entire brain" (vs some specific set of functions) and "accepted medical standards" (should they be specifically named?) and whether accommodations are needed to address religious or principled objections to determining death by neurologic criteria (DNC).<sup>6-9</sup> Here, we propose a solution to the alleged inconsistency between

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## Glossary

DNC = death by neurologic criteria; UDDA = Uniform Determination of Death Act.

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the meaning of “all functions of the entire brain” and “accepted medical standards” by transitioning from an anatomical approach to DNC to a functional approach, like the approach to death by circulatory criteria. This change will align the law with medical practice, bolster confidence among examiners in the reliability of the currently accepted medical standards, and transparently communicate to the public what the standards are expected to assess.

The currently accepted medical standards for DNC (published by the American Academy of Neurology in 2010 and the Society of Critical Care Medicine, American Academy of Pediatrics, and Child Neurology Society in 2011)<sup>10-12</sup> require documentation of an injury that explains the loss of brain function, the exclusion of confounding conditions, and a clinical examination that demonstrates unarousable unresponsiveness, brainstem areflexia, and apnea. Some argue that the absence of diabetes insipidus in many individuals who meet these standards indicates that some functions of the brain continue after pronouncement of death, namely those in the neurosecretory hypothalamus that regulate salt and water balance.<sup>13,14</sup> With this in mind, a *Nature* editorial argued, “The time has come for a serious discussion on redrafting laws that push doctors towards a form of deceit.”<sup>15(p570)</sup> To align the law with practice, either the “accepted medical standards” must include a more demanding set of tests that exclude neurosecretory functioning or the text requiring cessation of “all functions of the entire brain” must be revised.<sup>16,17</sup>

At some level, the criteria used to determine death must be a matter of convention and consensus.<sup>18,19</sup> The relevant question is not whether any brain functions remain, but rather whether those functions contradict a determination of death. Unlike consciousness, responsiveness, or spontaneous respiratory effort, outside of a discussion about the phrase “all functions of the entire brain,” the presence of neurosecretory functioning is not recognized as a contradiction to determination of death.<sup>20-25</sup> While we welcome further debate on its significance, we see no reason to reject the recommendations of consensus statements like that of the World Brain Death Project<sup>26</sup> that the persistence of neurosecretory function is consistent with DNC.

Therefore, we support revision of the UDDA to more accurately specify legal criteria that align with the medical standards: brain injury leading to permanent loss of (a) the capacity for consciousness, (b) the ability to breathe spontaneously, and (c) brainstem reflexes.<sup>3,4</sup> We term these amended criteria “neurorespiratory criteria.” We recognize that there may be different and competing reasons to believe why neurorespiratory criteria are appropriate, as there is even disagreement about this among ourselves, but we all

agree that the law would be more clearly aligned with practice if the phrase “all functions of the entire brain” were replaced with language clearly specifying neurorespiratory criteria. The use of neurorespiratory criteria is well-supported in the literature for physiologic and social reasons, justifying its use in the law.

## Worldwide Support for Neurorespiratory Criteria

The motivation to declare DNC arose in the context of the critical care setting in which some ventilator-dependent patients were found to be comatose, lacked the capacity to initiate breathing, and no longer had reflexes that mediate pupillary reaction to bright light, spontaneous eye-tracking of objects when the head is abruptly turned, and cough or gag responses.<sup>27</sup> According to the 1981 President’s Commission’s report,<sup>1</sup> which articulated justifications for the UDDA, neurologic criteria for death, like circulatory criteria, provide sufficient evidence for the death of the patient and are to be used if there is reason to believe circulatory functioning does not reliably indicate the presence of life.

Many of the arguments made by the President’s Commission in *Defining Death*<sup>1</sup> are consistent with the neurorespiratory criterion. The “whole-brain” formulation never meant that every neuron had to fail; rather, it was meant to contrast with the so-called “higher brain” formulation, according to which the permanent loss of consciousness alone is decisive for determining death. “What is missing in the dead,” the drafters argued, “is a cluster of attributes, all of which form part of an organism’s responsiveness to its internal and external environment.”<sup>1(p36)</sup> The relevant “cluster of attributes” becomes clearer in their explanation of the language of “all functions of the entire brain, including the brainstem:”

This may be thought doubly redundant, but at least it should make plain the intent to *exclude* any patient who has lost only “higher” brain functions or, conversely, who maintains those functions but has suffered solely a direct injury to the brain stem which interferes with the vegetative functions of the body. <sup>(p75, emphasis original)</sup>

Thus, if one is conscious or spontaneously breathes, one is not dead. While not explicitly stated, the implication is that if the cause of brain injury is known and confounding factors like hypothermia or drug intoxication are excluded, then permanent loss of the capacities for consciousness and the drive to breathe clinically indicate the permanent loss of the relevant “cluster of attributes” necessary for an organism to live.<sup>1(p36)</sup>

These attributes are clearly affirmed in the United Kingdom by the Academy of Royal Medical Colleges' *A Code of Practice for the Diagnosis and Confirmation of Death*<sup>28</sup>: "when the brainstem has been damaged in such a way, and to such a degree, that its integrative functions (which include the neural control of cardiac and pulmonary function and consciousness) are irreversibly destroyed, death of the individual has occurred."<sup>28(p13)</sup> As to the definition of death, the Academy of Royal Medical Colleges asserts that:

Death entails the irreversible loss of those essential characteristics which are necessary to the existence of a living human person and, thus, the definition of death should be regarded as the irreversible loss of the capacity for consciousness, combined with irreversible loss of the capacity to breathe.<sup>1(p11)</sup>

The relationship between the destruction of the brainstem's "integrative functions" and the irreversible loss of the capacities for consciousness and the drive to breathe could not be clearer. Supporters of the brainstem formulation of DNC in the United Kingdom have maintained for decades that neurorespiratory criteria are philosophically and culturally accepted, not only because of their critical importance for continued life, but also because they represent at the neurophysiologic level the departure of the "conscious soul" and the "breath of life."<sup>29,30</sup>

The President's Council on Bioethics' 2008 white paper *Controversies in the Determination of Death* is another landmark document that supports neurorespiratory criteria.<sup>31</sup> After reviewing the criticisms of the 1981 President's Commission's report, the majority view of the President's Council ("Position Two") was that DNC should be accepted as a way to determine the loss of the organism's capacity to perform its "vital work."<sup>31(p60)</sup> The authors noted that the loss of the organism's capacity to engage in need-driven interaction with its environment, sensing what it needs (oxygen) and acting to meet those needs (striving to take in air), is what marks the end of the organism.<sup>32</sup> This vital activity was explicitly operationalized in terms of neurorespiratory criteria: "If there are no signs of consciousness *and* if spontaneous breathing is absent *and* if the best clinical judgment is that these neurophysiologic facts cannot be reversed, Position Two would lead us to conclude that a once-living patient has now died" (emphasis original).<sup>32(p64)</sup> Like the UK model, Position Two further says, "From a philosophical-biological perspective, it becomes clear that a human being with a destroyed brainstem has lost the functional capacities that define organismic life."<sup>32(p66)</sup> Although the authors did not recommend changing the law to a "brainstem-only" formulation, they did clearly recommend using neurorespiratory criteria to determine what they call "total brain failure" (or DNC).<sup>33(p12)</sup>

Further support for neurorespiratory criteria can be adduced from 2 other representative professional societies. The Canadian Medical Association's 2006 report on the neurologic determination of death<sup>34</sup> recommends that the "concept and definition of neurologic death" be defined "as the irreversible loss of the capacity for consciousness combined with the

irreversible loss of all brain stem functions [named elsewhere in the document], including the capacity to breathe."<sup>34(p3)</sup> The WHO's 2012 statement on death criteria says, "Death occurs when there is permanent loss of capacity for consciousness and loss of all brainstem functions."<sup>35(p31)</sup> Although the capacity to breathe is not explicitly mentioned, its loss is implied as they recognize that "respiratory arrest" is "secondary to the loss of brainstem function."<sup>35(p13)</sup>

The most recent highly influential publication to acknowledge neurorespiratory criteria is the World Brain Death Project (2020), an international consensus statement endorsed by 5 world federations and numerous medical societies. The members recommended that neurologic criteria for death be defined as "the complete and permanent loss of brain function as defined by an unresponsive coma with loss of capacity for consciousness, brainstem reflexes, and the ability to breathe independently."<sup>26(p1081)</sup>

The President's Commission, the Royal Medical Colleges, the President's Council, the Canadian Medical Association, the WHO, and the World Brain Death Project all highlighted the importance of brainstem functioning for the capacities of consciousness and spontaneous breathing. The overlap of functions attributable to the brainstem nuclei—emotion, wakefulness and sleep, basic attention, and consciousness itself—are essential for the homeostatic balance of a living organism.<sup>36</sup> The principal nuclei involved in modulating cortical activation lie in the upper pons and midbrain, but lower brainstem structures have been also implicated. Detailed examination of the functions of all clinically accessible brainstem nuclei increases certainty that the functions of consciousness and spontaneous breathing have been permanently lost.

## Advantages of Neurorespiratory Criteria

We recognize that there can be varying philosophical, religious, cultural, metaphysical, or biological views on when death occurs, but it is necessary for the law to clearly stipulate legal criteria for determining death and for these criteria to align with medical standards.<sup>6</sup> As we have demonstrated, neurorespiratory criteria, which have the advantage of basing the determination of death on the loss of key vital functioning rather than anatomical mortality (e.g., "whole-brain death," "brainstem death," "cardiac death") or the presence of cellular electrical activity, are widely accepted and should be incorporated into the UDDA.

When the neurorespiratory criteria are satisfied, they afford just as bright a line between life and death as the accepted medical standards for circulatory criteria. Although this "bright line" is constructed for important social purposes (determining when the grieving process begins, when a marriage ends, when life insurance pays out, when constitutional rights no longer apply, when multiple vital organs can be procured, when requests for

autopsy are initiated, and when plans for burial begin<sup>39</sup>), it is rooted in observable facts, enabling confidence in the determination and the ability to make the distinction between life and death in a timely and efficient manner.<sup>34</sup>

Although additional revisions to the UDDA are necessary to address other concerns, such as whether the law should specify the medical standards themselves rather than loosely referring to “accepted medical standards,” or whether accommodations are needed to address religious or principled objections to DNC, we recommend that the first sentence of the UDDA be revised to reference cessation of neuro-respiratory functions to bring the law in alignment with practice. Rather than require “irreversible cessation of all functions of the entire brain, including the brainstem,” the UDDA should instead require “brain injury leading to permanent loss of (a) the capacity for consciousness, (b) the ability to breathe spontaneously, and (c) brainstem reflexes.”

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## Appendix (continued)

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# Disputes & Debates: Editors' Choice

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## Editors' Note: Infratentorial Brain Injury Among Patients Suspected of Death by Neurologic Criteria: A Systematic Review and Meta-analysis

In "Infratentorial Brain Injury Among Patients Suspected of Death by Neurologic Criteria: A Systematic Review and Meta-analysis," Briard et al. report that based on a review of 21 studies, the prevalence of (1) infratentorial brain injury among patients with suspected death by neurologic criteria (DNC) was 2%–16% and (2) isolated brainstem death was 1%–4%. Machado pointed out that a series of 4 patients with infratentorial brain injury who initially had isolated brainstem death subsequently progressed to whole-brain death. The study on these patients was included in Briard's review. He also commented that Jahi McMath, who was declared dead by neurologic criteria based on both clinical evaluation and ancillary testing after hypoxic-ischemic brain injury, had a lesion in her pons and was not dead by neurologic criteria because she did not have a complete intracranial circulatory arrest. This case has been discussed extensively in the literature, but Briard and Chassé did not offer comments on it. However, they agree with Machado that additional research is needed to understand the determination of DNC in patients with infratentorial brain injury.

Ariane Lewis, MD, and Steven Galetta, MD  
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## Reader Response: Infratentorial Brain Injury Among Patients Suspected of Death by Neurologic Criteria: A Systematic Review and Meta-analysis

Calixto Machado (Havana)  
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The article by Briard et al.<sup>1</sup> affirmed that infratentorial brain injury is relatively uncommon among patients suspected of death by neurologic criteria (DNC) and that isolated brainstem death seems to progress to whole-brain death in most cases.

On the contrary, Varelas et al. reported 4 patients with catastrophic posterior fossa injuries who fulfilled the UK criteria for DNC. Those 4 patients showed preservation of supratentorial cerebral blood flow (CBF), which disappeared between 2 and 6 days. This allowed for a diagnosis of DNC, according to the whole brain US criteria. Hence, the report concluded that if CBF assessment is used as an ancillary test, there is no difference between those patients and those who experience brain death due to supratentorial lesions.<sup>2–4</sup>

If a posterior fossa lesion does not produce extreme intracranial pressure, a complete intracranial circulatory arrest does not occur. For example, brain death was declared in the well-known case of Jahi McMath, but ancillary tests performed 9 months after the initial brain insult showed conservation of intracranial structures, EEG activity, and autonomic reactivity to the "Mother Talks" stimulus, rejecting the diagnosis of DNC. An MRI study of Jahi McMath's brain

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Author disclosures are available upon request (journal@neurology.org).

demonstrated a huge lesion in the pons.<sup>5</sup> Further research and discussion are necessary regarding the use of confirmatory tests for DNC diagnosis in the presence of primary posterior fossa lesions.

1. Briard JN, Plourde G, Nitulescu R, et al. Infratentorial brain injury among patients suspected of death by neurologic criteria: a systematic review and meta-analysis. *Neurology*. 2023;100(4):e443-e453. doi: 10.1212/WNL.0000000000201449.
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## Author Response: Infratentorial Brain Injury Among Patients Suspected of Death by Neurologic Criteria: A Systematic Review and Meta-analysis

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We thank Dr. Machado for the interest in our article on the prevalence, characteristics, and evolution of infratentorial brain injury and isolated brainstem death among patients suspected of death by neurologic criteria (DNC).<sup>1</sup>

The cited study by Varelas and colleagues<sup>2</sup> was included in our systematic review and contributed to its conclusions. Data from this study are represented in our mean prevalence estimates for both infratentorial brain injury and isolated brainstem death. Furthermore, the characteristics and evolution of isolated brainstem death patients described in this study were included among the 38 isolated brainstem death patients we found in the literature.

There is some evidence that the mechanism by which patients with isolated brainstem death eventually progress to whole-brain death includes progressive supratentorial hydrocephalus, intracranial hypertension, and venous drainage obstruction, but this evolution and its determinants have not yet been thoroughly validated in high-quality studies.<sup>3,4</sup> We agree that further research is necessary to determine the clinical significance of preserved cerebral blood flow, perfusion, or neurophysiologic function in patients with a clinical examination consistent with the DNC<sup>5</sup> and that expert consensus guidelines are needed to clarify how to best address individuals with brainstem areflexia after primary infratentorial brain injury.

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## Initial High-Efficacy Disease-Modifying Therapy in Multiple Sclerosis

### A Nationwide Cohort Study

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In the Research Article “Initial High-Efficacy Disease-Modifying Therapy in Multiple Sclerosis: A Nationwide Cohort Study” by Buron et al.,<sup>1</sup> 2 authors were mistakenly omitted from the final manuscript. Dr. Danny Bech, MD, should appear as author #5, and Dr. Sivagini Prakash, MD, should appear as author #14. The article has been replaced by a version with the correct byline. The original version with the changes highlighted is available from a link in the corrected article. The authors regret the omission.

### Reference

1. Buron M, Chalmer T, Sellebjerg F, et al. Initial high-efficacy disease-modifying therapy in multiple sclerosis: a nationwide cohort study. *Neurology*. 2020;95:e1041-e1051.

## Revise the Uniform Determination of Death Act to Align the Law With Practice Through Neurorespiratory Criteria

*Neurology*® 2023;100:496. doi:10.1212/WNL.0000000000201063

In the Contemporary Issues in Practice, Education, & Research article “Revise the Uniform Determination of Death Act to Align the Law With Practice Through Neurorespiratory Criteria” by Omelianchuk et al.,<sup>1</sup> 2 block quotes were inadvertently omitted under the Worldwide Support for Neurorespiratory Criteria section, with the authors’ words formatted as quotes. The article has been replaced by a corrected version. The original version with the changes highlighted is available from a link in the corrected article. The publisher regrets the errors.

### Reference

1. Omelianchuk A, Bernat J, Caplan A, et al. Revise the Uniform Determination of Death Act to align the law with practice through neurorespiratory criteria. *Neurology*. 2022;98(13):532-536.