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[UDDA Revision Series] Rethinking Brain Death—Why “Dead Enough” Is Not Good Enough: The UDDA  
Revision Series

**Author(s):**

Daniel P. Sulmasy, MD, PhD<sup>1</sup>; Christopher DeCock, MD, MS<sup>2</sup>

**Corresponding Author:**

Daniel P. Sulmasy, [sulmasyd@georgetown.edu](mailto:sulmasyd@georgetown.edu)

**Affiliation Information for All Authors:** 1. The Kennedy Institute of Ethics, Georgetown University; 2. Essentia Health & The University of North Dakota School of Medicine and Health Sciences

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**Abstract**

The emergence of cases of so-called “chronic brain death” appear to undermine the bio-philosophical justification of brain death as true death, which was grounded in the idea that death entails the loss of integration of the organism. Severely neurologically damaged patients who can persist for years with proper support appear to be integrated organisms and common sense suggests that they are not dead. We argue, however, that mere integration is not enough for an organism to be alive, but that living beings must be substantially *self-integrating* (i.e., a living organism must itself be the primary source of its integration and not an external agent such as a scientist or physician). We propose that irreversible apnea and unresponsiveness are necessary but not sufficient to judge that a human being has lost sufficient capacity for self-integration to be considered dead. To be declared dead, the patient must also irrevocably have lost either (1) cardiac function or (2) cerebro-somatic homeostatic control. Even if such bodies can be maintained with sufficient technological support, one may reasonably judge that the locus of integration effectively has passed from the patient to the treatment team. While organs and cells may

be alive, one may justifiably declare that there is no longer a substantially autonomous, whole, living human organism. This bio-philosophical conception of death implies that the notion of brain death remains viable, but that additional testing will be required to ensure that the individual is truly brain dead by virtue of having irrevocably lost not only the capacity for spontaneous respiration and conscious responsiveness, but also the capacity for cerebro-somatic homeostatic control.

The major reason for re-thinking brain death is the phenomenon dubbed “chronic brain death” (CBD) prominently exemplified by Jahi McMath, who lived for over four years after being declared brain dead.<sup>1,2,3</sup> During this time she underwent puberty. Insisting that such an individual was dead for four years seems unreasonable. The recognition of such cases has led to a variety of suggestions for revising the Uniform Determination of Death Act (UDDA), such as (1) tightening the criteria for diagnosis or (2) abandoning the idea of brain death.<sup>4</sup>

Some commentators have urged a third approach, changing the definition of brain death to fit current testing protocols.<sup>4,5,6</sup> This seems unreasonable. Were a test for multiple sclerosis to give too many false positives, neurologists wouldn’t change the definition of multiple sclerosis; they would improve testing. Similarly, if our clinical tests for brain death result in too many false positives, we should improve our testing, not change the definition of death.

Death ought not to be something physicians define by consensus. Physicians can, and should, set testing standards, but these standards should be based on a bio-philosophical conception of death—one that (1) encompasses ordinary cardiopulmonary death as well as neurological death, (2) is widely accepted, (3) objective, and (4) works for any biological species.<sup>7,8</sup> Such a conception was implicit in the work of the President’s Commission<sup>9</sup> and in the original UDDA.<sup>10</sup> That standard was the loss of integration,

founded on the belief that the brain was essential for the organismal unity of the body.<sup>11</sup> The challenges raised by CBD, however, require refining that conception.

### **A Bio-Philosophically Informed Standard for Determining Organismal Death**

We therefore propose a revised, bio-philosophically informed standard for the determination of death, a conception that makes clear that living organisms are not just integrated, but self-integrating:

*An organism that is judged to have irrevocably lost the fundamental capacity to be a substantially self-integrating, individual member of its biological kind, can be declared dead.*

This organismal conception of death works for an amoeba, a human being, and anything in between. Notably, however, the capacity for organismal self-integration becomes more complex up the evolutionary ladder. As shown in Figure 1, for human beings, we suggest that there are four fundamental functional sources of self-integration at the organismal level: mind-body integration, respiration, circulation, and cerebral homeostatic control.

Given this conception of organismal death and the delineation of these four fundamental sources of human capacity for organismal self-integration, we submit the determination of death is a threshold concept<sup>12</sup> that can be met when two necessary conditions plus one additional condition are satisfied (Figure 2).

*Necessary Conditions:* A) the irrevocable loss of conscious responsiveness, and B) the irrevocable loss of respiratory drive.

*Additional Conditions:* either C) the permanent cessation of circulation, or D) the irrevocable loss of cerebral homeostatic control.

A + B + C maps to the cardiopulmonary death—an unresponsive, breathless, and pulseless patient. A + B + D maps to what was originally intended by whole brain death<sup>8</sup>—an unresponsive, centrally apneic

patient with sufficient destruction of the brain such that cerebral homeostasis has been disrupted.

Patients meeting either conditions A + B + C or A + B + D can be judged to have lost the fundamental capacity to be substantially self-integrating individual members of the human natural kind.

In an Aristotelian sense, human beings are rational animals.<sup>13</sup> Loss of mind-body integration entails the loss of the rational, yet this loss alone only renders the patient damaged, not dead. Proponents of a “higher brain” standard of death would say that such individuals have died as persons.<sup>14</sup> Yet they have not died as substantially self-integrating organisms. What additional functions must be lost before a human being can be declared dead? Certainly the loss of respiration seems necessary. Respiration is an animal’s fundamental mode of interaction with its environment. Respiration, obtaining oxygen and dispelling carbon dioxide, is what permits metabolism. Respiration is also steeped in human symbolic history as a cardinal sign of life.

#### **How Much Self-integration Must Be Lost?**

Yet, is the irrevocable loss of both conscious responsiveness and the ability to breathe sufficient to declare someone dead? Even some observers who agree that death entails the loss of the capacity for self-integration have asserted that that these conditions suffice,<sup>15</sup> but it does not seem reasonable to say so. Common sense suggests that Jahi McMath was not dead. Likewise, a patient with post-coma wakeful unresponsiveness and a phrenic nerve injury is not dead. Both are cases of severely brain injured patients who irreversibly lack conscious responsiveness and cannot breathe independently. Yet such patients retain sufficient capacity for organismal self-integration that they could persist for prolonged periods with little support. Something more must be lost before one could reasonably declare a human being dead. We suggest that the threshold for having lost sufficient organismal self-integrative capacity to be declared dead is crossed by the additional loss of either cardiac function or cerebral homeostatic control.

The disruptive technology that initially provoked questions about the declaration of death was mechanical ventilation. Ventilators gave physicians the ability to resuscitate individuals who otherwise would have been declared dead very quickly following a pulmonary or cardiopulmonary arrest.<sup>16</sup> As shown in Figure 3, most humans still die without resuscitation. Where advanced resuscitation is available, humans may also now die by the failure of resuscitative efforts, or, given the proper justifying conditions, by forgoing resuscitation. The notion of brain death arose in response to a related question: could some patients also be declared dead *despite* resuscitation?

This was the question of the late 1950s, the one that led to the idea of brain death. Are there individuals who persist on ventilators, but are so damaged and require so much support that they are no longer self-integrating human organisms? When the locus of organismal integration becomes not the individual, but the treatment team, it would seem that such a threshold has been crossed. An individual who is unresponsive and apneic, but has also lost cerebral homeostatic control, as manifested by blood pressure and temperature instability, diabetes insipidus, lack of cerebral control over the hormones responsible for growth, metabolism, and sexual development and function, is no longer reasonably considered to be self-integrating.<sup>8</sup> The locus of integration has become the health care team that supplies all these functions artificially. Notably, to the best of our current scientific understanding, most of these functions are associated with the hypothalamus. Moreover, since thalamic function supports at least rudimentary consciousness, and cannot be tested directly, one can be more confident that the potential for consciousness has been lost if the functions of the adjacent hypothalamus have been disrupted. Thus, by the organismal standard we are proposing, an individual who has lost these functions in addition to having lost conscious responsiveness and respiratory drive, can be declared dead.

This is not to say that all integrative functions of the body have ceased, but rather that fundamental self-integration at the level of the organism has ceased. Cells continue to metabolize. Individual organs and

organ subsystems continue to function. Some hormonal, spinal cord, and peripheral autonomic functions persist.<sup>17</sup> But these do not suffice for declaring the patient alive as a substantially self-integrating individual organism. The distinction between organismal death and organ/cellular death is what makes transplantation possible.

Practically, this analysis would require either adding a direct assessment of cerebral homeostatic control to the clinical criteria used to determine brain death, or additional testing to ensure that all the critical integrative functions of the brain, including those of the hypothalamus, have been irrevocably damaged.<sup>8</sup> Whether this includes physiological assessment, endocrinologic testing, and/or improved evaluation of cerebral circulation are matters for scientific debate.<sup>18,19,20,21,22</sup> Absent evidence of the loss of cerebral homeostatic control of the body, however, the individual could not be declared dead by neurological criteria.

Since the early cases of brain death all exhibited very severe damage, explicit hypothalamic testing was superfluous: apnea and the absence of consciousness and brain stem reflexes were assumed to be sufficient to diagnose death of the entire brain, including the hypothalamus. These individuals all displayed signs of neurohormonal and autonomic instability and thus it became the common understanding that none could persist long even with maximal support.<sup>23,24,25, 26,27,28,29</sup> CBD cases only emerged later, as the scope of cases widened and the capabilities of intensive care units increased. Current diagnostic testing standards do not rule out persistent hypothalamic function.

### **Potential Counter-arguments**

What are the counter-arguments against requiring evidence of cerebral homeostatic dysfunction before the declaration of brain death? One is that neurologists have arrived at a consensus on standards for determining brain death and simply to assert, “that’s not how we do it.”<sup>5,6</sup> Such an assertion, however, is neither biomedically satisfying nor philosophically adequate. Praxis ought to *follow* a definition; praxis



does not *constitute* the definition. No one is dead simply because someone has decided to call them dead.

Others have questioned whether the hypothalamus should be considered part of the brain,<sup>5,30</sup> or have downplayed the importance of hypothalamic function,<sup>6,31,32</sup> or have admitted that those declared brain dead yet evidencing hypothalamic function are not really dead, but “dead enough” to be organ donors.<sup>33</sup>

Yet it seems wrongheaded to re-write neuroanatomy in order to advance a definition of death.

Moreover, denigrating the importance of the hypothalamus suggests an implicit commitment to a higher brain conception of death. The metabolic and autonomic integrative functions subserved by the hypothalamus are critical to life.

A third argument is to observe that the modification we suggest will result in fewer people being declared brain dead and therefore diminish the supply of organs.<sup>34</sup> This not an adequate response. First, a good motive does not make an action right. Second, such arguments provide fodder for the deep and, widely held (but historically questionable) public suspicion that brain death is not real death but something doctors “made up” to facilitate organ transplantation.<sup>35</sup> Third, the impact on organ donation might not be as great as imagined. Profoundly neurologically injured individuals who are not brain dead could still be organ donors by donation after circulatory determination of death (DCDD). Success rates in heart transplantation after DCDD are improving rapidly.<sup>36</sup>

Lastly, one might suggest that our proposal is arbitrary. Why not just declare someone dead when they have permanently lost consciousness? Our proposal, however, is far from arbitrary. It comports with common sense. It includes as necessary the widely accepted conditions of apnea and loss of conscious responsiveness. Importantly, it grounds the judgment of sufficiency in a bio-philosophical conception of death—that living organisms are substantially self-integrating. A human being who is irreversibly unconscious and dependent upon a ventilator but can maintain her own blood pressure,

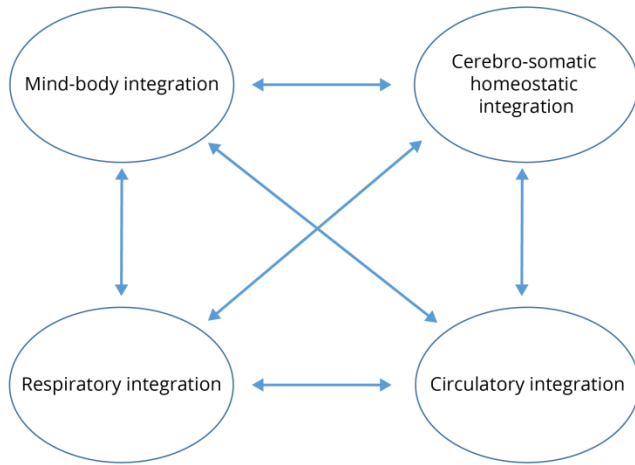
thermoregulation, sodium balance, growth, and metabolism is still substantially self-integrating and therefore not dead.

## **Conclusion**

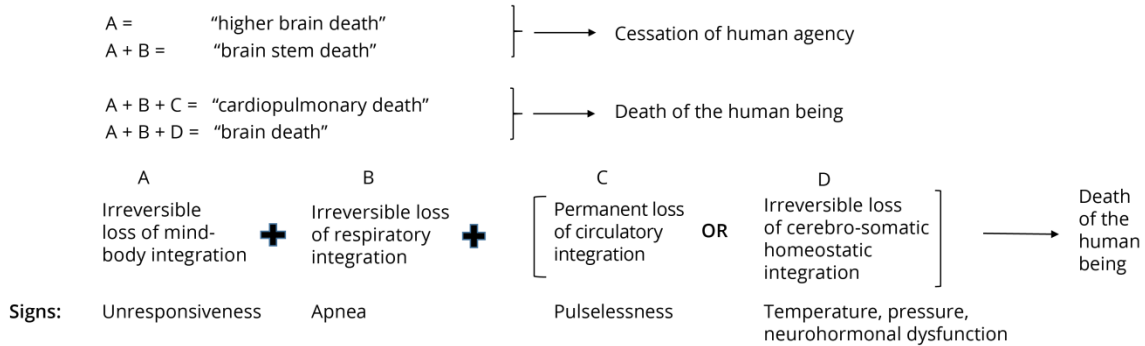
Death is not a neurological state of a living human being—it is the end of a human life. The emergence of cases of CBD therefore necessitates a re-examination of what is required to judge a human being to be dead by neurological criteria. The original philosophical conception of death that was used to justify the notion of brain death, the loss of integration at the organismal level, still stands. The irrevocable loss of the critical, organismically integrative functions of the brain meets that standard. What the CBD cases demonstrate, however, is that certain functions that are fundamental to organismal integration persist in some patients diagnosed as brain dead by current clinical standards, allowing them to continue to live for long periods of time with minimal support. From this it follows that additional testing will be required to assure that *all* of the critical, integrative functions of the brain have ceased if the determination of brain death is to be accurate. Against those who would argue that the emergence of cases of CBD refutes the notion that these patients have lost organismal integrative function, we have argued that the mere passive persistence of integration is not sufficient for being a living organism. The cells of a tissue culture are alive in this sense, and even communicate and exhibit rudimentary integration. But a tissue culture is not a living organism. The source of integration in a living organism should originate substantially within the organism itself, not in the acts of a scientist or a physician. One must then judge when the threshold has been reached for saying that the locus of organismal integration has substantially passed from the patient to the medical care team. We have argued that patients who have irrevocably lost the fundamental capacity for mind-body integration, respiratory drive, and cerebral homeostatic control have lost sufficient self-integration that they can be judged to have died. Thus, there *is* such a thing as brain death, but it requires more than apnea and the loss of

conscious responsiveness to determine it. We don't need to abandon the concept of brain death—we just need to improve our testing.

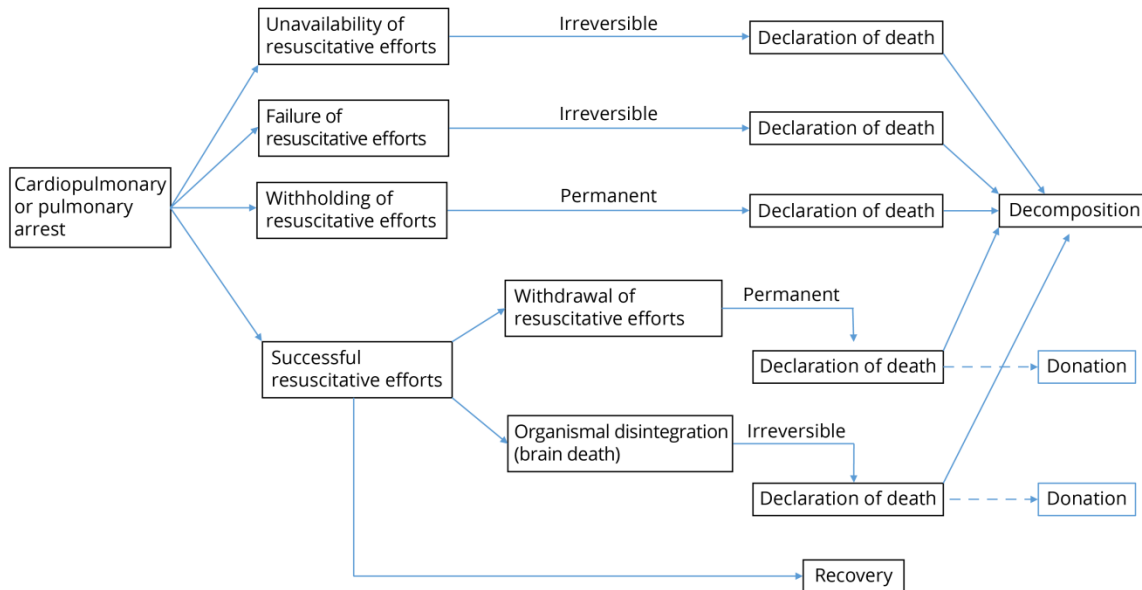
**Figure 1. Fundamental spheres of human organismal self integration**



**Figure 2. Proposed criteria for death with respect to fundamental human capacities for organismal self-integration**



**Figure 3. Paths to death in light of the technical medical capacity for resuscitation**



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