



Neurocritical  
Care Society

# **BRAIN DEATH**

**Frequently Asked  
Questions**  
for the General Public

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## BRAIN DEATH FAQ's FOR THE GENERAL PUBLIC

### NEUROCRITICAL CARE SOCIETY

1. **Q: Why was this FAQ created?**

**A:** Several national surveys indicate that there is widespread misunderstanding about brain death - by the public as well as the news media. Each year, there are approximately 15,000 to 20,000 deaths by brain death, and, as our population ages, these numbers may increase. Thus, members of the general public are increasingly searching for information about brain death, and they often find conflicting definitions of the term. Well-intentioned but misinformed reporting has resulted in increased confusion. The Neurocritical Care Society, an organization comprised of many of the world's top clinical neuroscience experts, decided to publish this FAQ to shed light upon this topic and dispel the most common misunderstandings.

2. **Q: Who is the intended audience for this FAQ?**

**A:** The audience is the general public, including families, patients, and anyone seeking clarification on the subject of brain death.

3. **Q: Why is Brain Death so confusing?**

**A:** We agree that the topic of brain death can be confusing. In the case of brain death, the brain no longer functions, meaning that the patient has suffered injuries so severe that they cannot possibly recover. The patient has passed away. And yet the patient might appear to be sleeping because he or she seems to be breathing and still has a beating heart. We can see how this can be misleading to anyone viewing the body. The breathing appearance comes from the ventilator (breathing machine), and this allows the heart to keep beating. As soon as the machine is disconnected, breathing and the heart beating will stop. It can be hard for families to grasp the finality of their loved one's death in the wake of these conditions.

4. **Q: Does this FAQ replace advice from my doctor?**

**A:** We consider the "in person," face-to-face exchange between physician and patient/family to be the gold standard. Every patient's case is different. This FAQ offers general guidelines to help the general public understand the concept of brain death. This FAQ is not a substitute for a direct conversation with your physician.

5. **Q: What is brain death?**

**A:** Brain death is the permanent loss of function of the entire brain, including the brain stem. Physicians with specific expertise determine that brain death has occurred using a very specific approach to assure that the determination is approached correctly.

Physicians are careful to eliminate any problems that can occasionally make a living patient appear dead. One important test called an "apnea test" is performed as part of brain death determination, and it shows that even one of the most basic functions of the brain stem is lost (the drive to breathe). There is a very specific approach to the apnea test that is taken by the physician to affirm that the patient has lost the drive to breathe.

When a patient is brain dead, he/she has permanently lost function of the entire brain, but the heart is still beating because of machines and medications that are being used. It is equivalent to death by the stoppage of breathing circulation, but the machines give a living appearance to the patient. For this reason, it is important to understand that breathing machines are not considered "life support" in a brain dead patient, since the patient's death has already been pronounced.



6. **Q: What causes brain death?**

**A:** There are many causes of brain death. The most important idea is that it is due to a catastrophic injury to the brain. Some of the more common causes are blocked blood vessels to the brain, burst blood vessels in the brain, brain trauma, cardiac arrest, brain infections, sudden liver failure, and other causes of severe brain swelling.

7. **Q: How is brain death diagnosed?**

**A:** First and foremost, the cause of the brain injury must be known with its effect on the brain being permanent. This is a critical starting point that must be satisfied before brain death determination is made. Second, problems that can make the brain injury look worse than it really is (certain drugs, medications, or blood abnormalities) must be identified and considered in the approach to brain death determination. Third, a highly detailed neurological examination is performed to show that there is no brain function. This includes such things as confirming coma, the loss of reactions to light, the loss of all eye movement reflexes, and loss of non-reflex movements. Sometimes movements can be seen that come from the spinal cord – not the brain.

The final portion of the examination is called the “apnea test.” This is done to show that the brainstem, which is the lower portion of the brain responsible for many automatic functions, is no longer controlling breathing. There is a very specific way to prepare for this test and then to conduct it. In this test, the patient’s ventilator is typically removed, and he or she is observed to see if any effort of breathing is present. This test occurs over at least an 8 minute period, during which time the carbon dioxide level must rise above a certain level that would drive breathing if the brainstem were functioning. Upon the completion of the apnea test, the patient’s death is declared.

If for some reason the clinical examination cannot successfully be performed (for example, when there are persistent sedating drugs in the bloodstream, or there is significant injury to the face making parts of the clinical examination impossible), an “ancillary test” can be performed. There are several types of tests, but in general they look for an absence of blood flow to the brain, or, sometimes, an absence of electrical activity in the brain.

8. **Q: What happens to a person once brain death is diagnosed?**

**A:** Brain death is a medical and legal determination of death. By definition, there is no recovery from brain death – or death by any mechanism, when it has been determined properly. The body may be supported by artificial means for limited periods of time, either to have family gather or for possible organ donation, but most often the other organs will fail over time despite artificial support. If patients are not suitable for organ donation, artificial organ support is removed. Machines are not maintained on dead people.

9. **Q: How did brain death come to be?**

**A:** Brain death did not exist before the creation of ventilators, which are machines that breathe for patients who are unable to breathe on their own. Before ventilators, patients who suffered severe brain injuries simply died due to their injuries when they were severe enough to affect breathing or heart function. However, once technology was developed that allowed for the artificial support of the other organs, a new way to declare death was necessary. Determining the occurrence of death in people with a heart beating, brain death– is often called death by neurological criteria, and the concept and approach to this determination was developed after mechanical ventilation was more widely used in the late 1950’s and 1960’s. Subsequently, physicians, and later government and state bodies, developed and adopted strict policies to ensure that brain death determination is performed correctly, and in accordance with medical standards and state laws.

10. **Q: Don’t you need a brain scan or a brain wave test for brain death?**

**A:** By most state laws in the United States, a brain scan testing for blood flow, or a brain wave test (EEG) is not required, but they may be useful as part of the brain death determination in specific circumstances. A CT scan or some form of neuroimaging is necessary to evaluate for the presence of a neurological catastrophe.

11. **Q: How can they be dead if their heart is still beating?**  
**A:** Death in brain death is defined by the permanent loss of function of the entire brain while the patient is on machines that maintain the heart beating. Without those machines the patient would be cold, blue and without breathing immediately and without a heart beat within minutes.
12. **Q: What if they appear to be responding to my voice?**  
**A:** A response to voice should be seen in brain death, and if present, the diagnosis of brain death should be questioned and the response explained. It is important to note that sometimes patients who are brain dead will show movements that are produced by the spinal cord and not from the brain. These include certain movements in the arms and legs in response to specific physical stimulation. These movements can be mistaken as a response from the patient while in fact they do not represent any brain function.
13. **Q: I understand that the apnea test means stopping the ventilator for at least eight minutes. If the test is performed on someone who is not brain dead, could the test harm a vulnerable patient by taking away his/her breathing for such a long time? In other words, are there side effects of the test that may be worrisome?"**  
**A:** Apnea testing should only be performed as a final diagnostic step when a patient has already had confirmation of a devastating brain injury incompatible with meaningful recoverability. It should only be done after all other testing is compatible with brain death. In this context, the apnea test cannot alter the already defined unfortunate outcome. Cardiac arrest is extremely rare during brain death testing, and great care is taken to ensure that the vital functions are maintained stably during apnea testing.
14. **Q: If an apnea test indicates brain death, will the doctor reconnect the ventilator at the end of the test?**  
**A:** Yes. Once apnea testing is performed, the ventilator will be reconnected. This will allow time for return of the necessary blood test results and the face-to-face discussion between the health care team and the patient's loved ones to explain the patient's death and the next steps.
15. **Q: If an apnea test indicates brain death, is it appropriate for the doctor to pronounce the time of death?**  
**A:** The time of death is the time that the blood work drawn during the apnea test shows the accumulation of carbon dioxide to the required threshold, or the time of the formal interpretation of any additional tests that were deemed necessary. This time of death, by definition, will be at a time when the heart is still beating because the patient is still on the ventilator.
16. **Q: Is brain death the same as a coma?**  
**A:** No. Coma refers to a severely depressed level of consciousness, with complete unresponsiveness. In brain death, the patient has completely and irreversibly lost all brain function, and the patient is dead.
17. **Q: Is brain death the same as a vegetative state?**  
**A:** No. Vegetative state refers to a patient who is alive but has a brain injury that prevents awareness. These patients often have continued function of the brainstem that allows continued capacity to breathe, and they may have wakefulness. However, they lack any awareness or meaningful interaction with their environment or those around them.
18. **Q: What if there is still some brain activity detected on a brain wave test (electroencephalogram or EEG)? Is the patient still brain dead?**  
**A:** Continued brain activity on an EEG is not compatible with brain death. Notably, there is a very specific protocol to conduct an EEG to determine if there are brain waves to support the clinical diagnosis of brain death. Part of the proper interpretation of the EEG requires recognizing the difference between real brain wave activity and artifacts (electrical noise from the environment).



19. **Q: Has anyone ever recovered from brain death?**  
**A:** No. Death is permanent. If anyone claims to have recovered from brain death, then the diagnosis was incorrect.
20. **Q: Shouldn't doctors wait a while to disconnect the ventilator, just in case the patient might come back?**  
**A:** Brain death is diagnosed after a series of defined and standardized tests on a patient with a severity of brain injury that can lead to death. One of these tests is the apnea test. If the clinical situation and the tests have led to the determination of brain death, then this means the patient cannot recover; brain death is death, which is irreversible. Keeping a body on a ventilator after brain death has been declared properly will never result in recovery. Once a patient has died, a ventilator and other medical treatments may maintain the body's circulation for some period, but the machine is not keeping the patient alive. The person is dead.
21. **Q: A patient was declared brain dead, but he doesn't look like he has died. His coloring is good and he looks like he is sleeping. But the doctors and nurses are saying he is dead. How does that make sense?**  
**A:** The machines and medical treatments that are provided to brain dead patients in a critical care unit allow a continued heart beat and circulation that creates the appearance of a sleeping patient even after death has occurred.
22. **Q: How can a patient be declared brain dead but still have some organs that are working? Don't working organs indicate there is still life?**  
**A:** The mechanical ventilator and various medications that are provided to the brain dead patient allow a continued heartbeat and circulation, which keeps most of the vital organs working (except the brain). Organs can often be kept working for a period of time, even outside of the body.
23. **Q: Do the spending limits of a patient's insurance plan influence the diagnosis of brain death?**  
**A:** No. The diagnosis of brain death is entirely independent of insurance plans or any other financial considerations. It is a doctor's obligation to pronounce a patient's death when it occurs. This obligation is about the occurrence of death and not the patient's insurance plan.
24. **Q: Can't the brain sometimes heal itself? There are stories on the news about how brains can keep changing and learn to recover. And what about the latest clinical trials – isn't there something out there to try? Some patients are fighters and would want to try anything to come back for their families.**  
**A:** Brains often heal from various injuries. For instance, some stroke patients are able to regain functioning after considerable therapy. However no one can recover from brain death. If the clinician has any doubt as to whether there can be even minimal recovery, brain death is not declared. A determination of brain death means that the patient has died; brain death is irreversible. In fact, there is no clinical trial, transplant, surgery, medication, or treatment that can reverse brain death.
25. **Q: I understand that my doctors are telling me that my loved one is dead because he is brain dead. But we are a deeply religious family, and what the doctors are saying doesn't seem to resonate with my cultural or religious beliefs. I don't know what to do.**  
**A:** Voice your concerns to your doctor, your nurse, a social worker, or anyone with whom you feel comfortable. You can also bring your religious leader or a trusted friend to the hospital and have them meet with you and the hospital team. Expressing your concerns is valid and at least warrants a discussion so that you can better understand brain death and how it is managed.

26. **Q: What if a patient's living will or advance directives clearly state that they want all extraordinary measures to be taken to prolong their life?**
- A:** In general medical practice, efforts should indeed be made to honor a patient's documented wishes. However, a brain dead patient is dead and recovery is not possible. This is a circumstance that is beyond the direction provided by a living will or advanced directive. No advanced directive can legally dictate continuing medical treatments on a dead patient.
27. **Q: What if a family continues to feel uncomfortable with the diagnosis or concept of brain death?**
- A:** First and foremost, the family should discuss these concerns with the treating medical team, asking for more discussion so that they can better understand. Sometimes it is helpful for families to witness the brain death examination and apnea test, so that they can see for themselves that their loved one does breathe on their own, even after a long period of time. They may also request an ethics consult. Every hospital is required to involve some kind of ethics service. Both of these options have staff members who may review the patient's circumstances and see how they may help resolve any conflicts or miscommunications. The family might also consider bringing a trusted friend or advisor to the hospital, such as their clergy. They can meet with hospital staff together to talk about their discomfort and learn about appropriate next steps.