Brain Death FAQs for the lay public

Several national surveys indicate there is widespread misunderstanding about brain death, by both the public and the news media. Each year there are approximately 15,000 to 20,000 people declared dead by neurologic criteria and, as our population ages, these numbers may increase. Thus, members of the public are increasingly searching for information about brain death, and they often find conflicting and incorrect information. Well-intentioned but misinformed reporting has resulted in increased confusion. The Neurocritical Care Society, an organization comprised of many the world's top clinical neuroscience experts, presents this FAQ to shed light upon this topic and dispel the most common misunderstandings. The intended audience is the general public, including families, patients, journalists, and anyone seeking clarification on the subject of brain death.

Question 1: *Why is brain death so confusing?*

We agree that the topic of brain death can be confusing. Brain death is declared when the brain no longer functions due to a severe catastrophic permanent injury from which the patient cannot possibly recover. Brain death declaration requires careful exclusion of any other conditions that may impair brain function and then a detailed examination described below. This is legal death. The patient might appear to be sleeping because machines are circulating their blood and moving the lungs to facilitate breathing. This can be misleading to anyone viewing the body. In brain death, breathing is facilitated by a ventilator (breathing machine) which allows the heart to keep beating. When a person does not have brain function, as soon as the machines are disconnected, breathing will stop and eventually the heart with stop beating. It can be hard for families to grasp the finality of their loved one's death in the wake of these conditions.

Question 2: *Does this FAQ replace advice from my doctor?*

In person, face-to-face exchange of information between a clinician and patient/family cannot be replaced by information found online because every patient's case is different. This FAQ offers guidelines to help the general public understand the concept of brain death. It does not a substitute for a direct conversation with a clinician.

Question 3: *What is brain death?*

Brain death is the permanent loss of function of the entire brain, including the brainstem, which is located at the base of the brain and is responsible for the most basic functions, such as breathing, blinking when the eye is touched, or coughing when the throat is irritated. Clinicians with expertise in catastrophic brain injuries perform evaluations for brain death using a detailed approach to assure that the evaluation is performed correctly.

Clinicians carefully eliminate any conditions that can make a living patient appear dead, like low temperature or low blood pressure or sedating medications. They then perform a detailed examination to assess for brain function, as described below. This includes a very important test called an "apnea test," to evaluate if the brain can initiate breaths when not connected to the breathing machine.

When a patient is brain dead, they have permanently lost function of the entire brain, but the heart is still beating because of machines and medications that are providing organ support. Brain death is medically and legally equivalent to the traditional criteria for death (cessation of breathing and circulation), but the machines may make it appear as though a brain-dead person is alive. For this reason, it is important to understand that a breathing machine is not considered "life support" in a brain-dead patient, since the patient's death has already been pronounced and they are legally dead.

Question 4: *What causes brain death?*

There are many causes of brain death. Some of the more common causes are blocked blood vessels to the brain leading to stroke, burst blood vessels in the brain leading to a bleed, brain trauma, cardiac arrest, brain infections, liver failure, and other causes of severe brain swelling. Any of these conditions can cause permanent catastrophic injury to the whole brain causing loss of all brain function, i.e., brain death.

Question 5: *How is brain death diagnosed?*

First and foremost, the cause of the brain injury must be known prior to brain death evaluation, and it must be known that its effect on the brain is catastrophic and permanent. This is a critical starting point that must be satisfied before brain death evaluation is initiated. Second, problems that can make the brain injury look more injured than it really is (low blood pressure, low temperature, certain drugs/medications) must be identified and corrected. 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 pupillary constriction in response to light, the loss of all eye movement reflexes, and loss of non-reflexive brain-mediated movements of the face and limbs. Notably, there can sometimes be movements that come from the spinal cord, muscles, or nerves, as these are not impacted by brain death (only the brain and brainstem is impacted).

The final portion of the examination is called the "apnea test" which is done to evaluate whether there is any remaining brainstem control of breathing. There is a very specific way to prepare for this test and conduct it. In this test, the patient's ventilator is typically removed, and they are observed to see if any effort of breathing is present during at least an 8-minute period, allowing the carbon dioxide level (a toxin that the lungs get rid of from the body) to rise above a certain level. In a patient with a functioning brainstem, this should drive breathing. Upon the completion of the apnea test, if there are no spontaneous breaths from the patient once the required rise in carbon dioxide level is achieved, death is declared.

If, for some reason, the clinical examination cannot successfully or safely be performed (for example, if there is significant injury to the face making parts of the clinical examination impossible), an "ancillary test" or extra test is performed in addition to the clinical exam components that can be tested. There are several types of tests, but in general they look for an absence of blood flow to the brain.

Question 6: *What happens to a person once brain death is diagnosed?*

Brain death is a medical and legal determination of death. By definition, there is no recovery from brain death – or death by any mechanism. The next step after brain death determination is discontinuation of the ventilator (note that at this time the patient is already legally dead). However, patients who are brain-dead may be organ donors, so if the patient/family elect to proceed with organ donation, the body will be supported by artificial means until donation. Machines are not maintained on dead people.

Question 7: *How did brain death come to be?*

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 injuries when they were severe enough to affect breathing or heart function. However, once technology was developed that allowed for the artificial support of breathing and circulation, 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 1950s and 1960s. Subsequently, physicians, and later government and state bodies, developed and adopted strict policies to ensure brain death determination is performed correctly, and in accordance with medical standards and state laws.

Question 8: *Don't you need a brain scan or a brain wave test for brain death?*

All patients with a catastrophic brain injury have standard pictures taken of their brain, such as a CAT scan or MRI, to ensure that the injury is severe enough to cause brain death and is permanent. A brain scan testing for blood flow is not required for brain death determination in most situations. A brain wave test (EEG) is not part of the brain death evaluation because it does not evaluate the brainstem.

Question 9: *How can a person be dead if their heart is still beating?*

Death by neurologic criteria is defined by the permanent loss of function of the entire brain. In brain death, machines facilitate breathing which allows the heart to keep beating. Without those machines the patient would be cold and blue, would not breathe, and their heart beat would stop within minutes due to a lack of oxygen.

Question 10: *Can a brain-dead person respond to voice?*

Sometimes patients who are brain dead will show movements that are produced by the spinal cord, muscles, or nerves, but by definition, a brain-dead person does not have function of the brain or brainstem. Movements of the face or arms and legs that are produced by the spinal cord, muscles, or nerves can be seen in response to specific physical stimulation. These movements are stereotyped and are not purposeful. A response to a voice cannot be seen in brain death, and if present, the diagnosis of brain death should be questioned, and the response explained.

Question 11: *I understand that the apnea test means stopping the ventilator. If the test is performed on someone who is not brain dead, could the test harm a vulnerable patient by taking away their breathing? In other words, are there side effects of the test that may be worrisome?"*

Apnea testing should only be performed as a final diagnostic step when a patient has already been found to have a permanent catastrophic brain injury incompatible with meaningful recoverability and an examination that shows no evidence of brain function. It should only be done after all other testing is compatible with brain death. In this context, the apnea test cannot cause further injury to an already severely damaged brain. Patients are monitored closely during the evaluation to ensure their blood pressure and oxygenation are normal and the test is aborted if there is concern for instability.

Question 12: *If an apnea test indicates brain death, will the doctor reconnect the ventilator at the end of the test?*

Yes. Once apnea testing is performed, the ventilator will be reconnected. This will allow time for the necessary blood test results to be reviewed to assess whether they are consistent with brain death (if not completed prior to reconnecting the ventilator) and the face-to-face discussion between the health care team and the patient's loved ones.

Question 13: *If an apnea test indicates brain death, is it appropriate for the doctor to pronounce the time of death?*

The official 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 where an alive patient would have taken a breath, 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 breathing because the patient is still on the ventilator.

Question 14: *Is brain death the same as a coma?*

No. Coma refers to a severely depressed level of consciousness, with complete unresponsiveness, but preservation of brainstem function, and the potential for recovery. In brain death, the patient is not in a coma, but has completely and permanently lost all brain function, and the patient is dead.

Question 15: *Is brain death the same as a vegetative state?*

No. Vegetative state refers to a patient who is alive but has a brain injury that prevents awareness. These patients 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.

Question 16: *Has anyone ever recovered from brain death?*

No. Death is permanent. If anyone claims to have recovered from brain death, then they are misusing the term "brain death" or the evaluation was incorrect.

Question 17: *Shouldn't doctors wait a while to disconnect the ventilator, just in case the patient might come back?*

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 permanent. 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.

Question 18: *A patient was declared brain dead, but they don't look like they have passed away. Their color is good, and they look like they are sleeping. The doctors and nurses are saying they are gone. How does that make sense?*

The machines and medical treatments allow a continued heart beat and circulation that creates the appearance of a sleeping patient even after death has occurred.

Question 19: *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?*

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).

Question 20: *Do the spending limits of a patient's insurance plan influence the diagnosis of brain death?*

No. The diagnosis of brain death is entirely independent of insurance plans or any other financial considerations. It is a clinician'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.

Question 21: *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.*

People can recover from various brain 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 permanent. There is no surgery, medication, or other treatment that can reverse brain death.

Question 22: *I understand that my clinicians are telling me that my loved one is dead because they are 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.*

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 warrants a discussion so that you can better understand brain death and how it is managed. Your clinicians should handle your religious concerns with respect and understanding, and involving clergy of the patient's faith can be very helpful to understand the stance of that particular religion as it pertains to death, and brain death in particular.

Question 22: *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?*

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.

Question 23: *What if a family continues to feel uncomfortable with the diagnosis or concept of brain death?*

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 not breathe on their own, even after a long period of time. They may also request an ethics consult. Every hospital is required to have some kind of ethics service. Both 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.