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Debate simmers over when doctors should declare brain death

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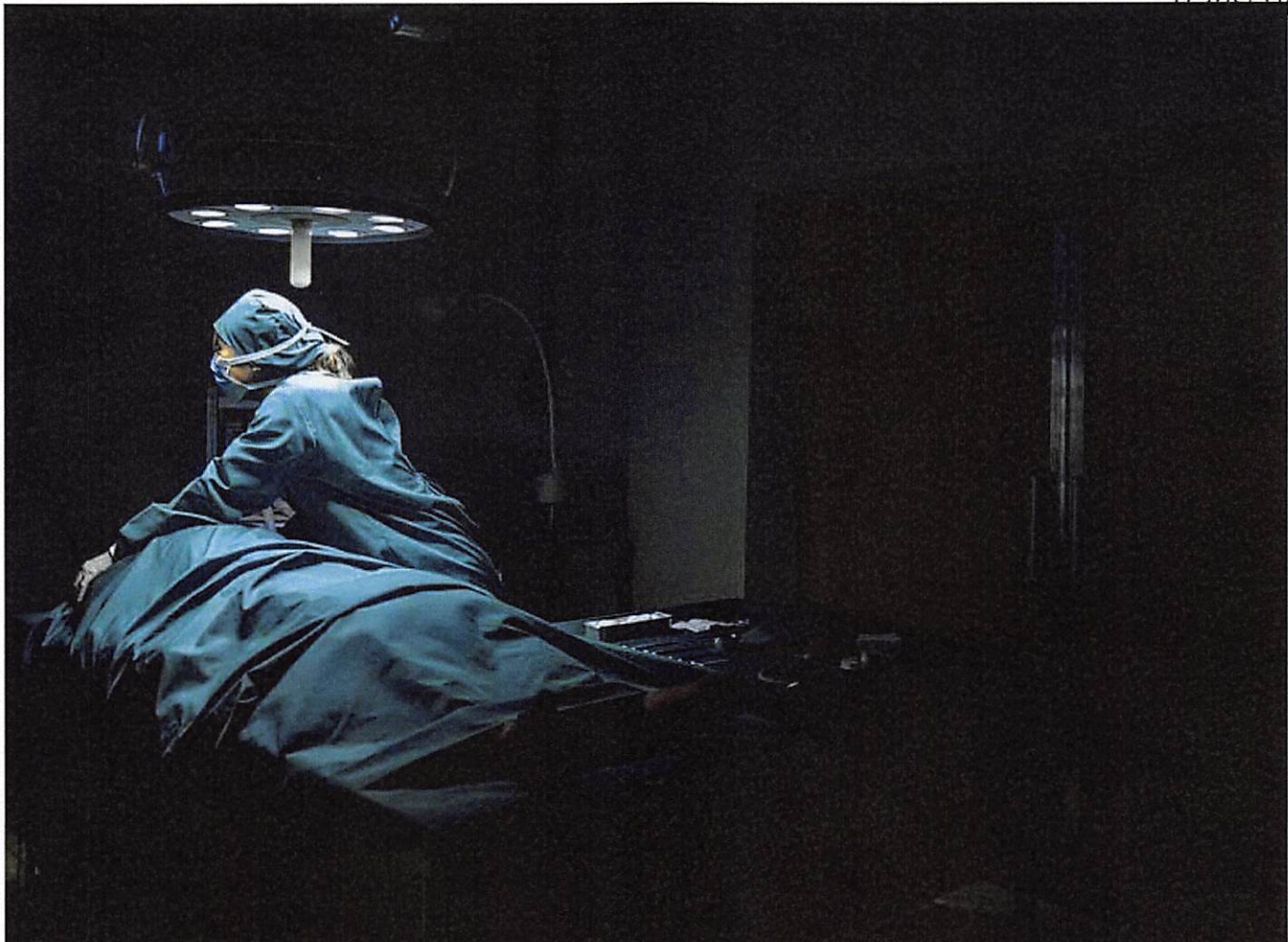
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When can a person be declared dead? The question can be hard to answer.

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Benjamin Franklin famously wrote: "In this world nothing can be said to be certain, except death and taxes."

While that may still be true, there's a controversy simmering today about one of the ways doctors declare people to be dead.

The debate is focused on the Uniform Determination of Death Act, a law that was adopted by most states in the 1980s. The law says that death can be declared if someone has experienced "irreversible cessation of all functions of the entire brain."

But some parts of the brain can continue to function in people who have been declared brain dead, prompting calls to revise the statute.

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Many experts say the discrepancy needs to be resolved to protect patients and their families, maintain public trust and reconcile what some see as a troubling disconnect between the law and medical practice.

The debate became so contentious, however, that the Uniform Law Commission, the group charged with rewriting model laws for states, paused its process last summer because participants couldn't reach a consensus.

"I'm worried," says Thaddeus Pope, a bioethicist and lawyer at Mitchell Hamline School of Law in St. Paul, Minnesota. "There's a lot of conflict at the bedside over this at hospitals across the United States. Let's get in front of it and fix it before it becomes a crisis. It's such an important question that everyone needs to be on the same page."

Criteria for brain death are the challenge

There are two ways doctors can declare someone dead. The original method, which remains the most common, is known as circulatory death. It occurs when someone stops breathing permanently and their heart stops beating permanently, such as from a heart attack. This method is applicable if CPR or breathing machines are unsuccessful or will not be used.

The second method, brain death, can be declared for people who have sustained catastrophic brain injury causing the permanent cessation of all brain function, such as from a massive traumatic brain injury or massive stroke, but whose hearts are still pumping through the use of ventilators or other artificial forms of life support.

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For years, doctors have declared brain death using a series of tests to determine four main criteria: whether a person has a profound and irreversible coma, has permanently lost the capacity to breathe, has permanently lost all reflexes controlled by the brainstem, and whether all potentially reversible conditions, such as a drug overdose, have been ruled out.

But other parts of the brain may continue to function. Specifically, attention has focused on the hypothalamus, which helps manage very basic bodily functions like temperature, blood pressure and hormones.

"The law says: You're not dead until all the functions of your entire brain have stopped — every single function of the entire brain," Pope says. "Well, there is a function of your brain that may continue, and we're still going to say that you're dead."

Critics point to rare cases like Jahi McMath, a 13-year-old girl who was declared brain dead in 2013. Her family refused to withdraw life support for years. She continued to grow and even went through puberty. Jahi never recovered and eventually died. But her case and others have prompted calls to change the law.

"I've never heard of a corpse that underwent puberty before," says Dr. D. Alan Shewmon, a professor emeritus of pediatrics and neurology at the David Geffen School of Medicine at the University of California, Los Angeles, who has long questioned the use of brain death. "She was clearly not dead. Yet she was declared dead. I think it's a tragedy. How many others are potentially like that but we never find out?"

When does hope for recovery end?

But many other neurologists, bioethicists and others argue that there's no way to make sure every neuron in the brain has ceased functioning. Even if someone still has activity in some parts of the brain, such as the hypothalamus, they won't wake up or recover if they have been declared brain dead correctly through current testing, they say.

"They do not have any hope for meaningful recovery or any hope for regaining of consciousness or brainstem function," says Dr. David Greer, chair of neurology at the Boston University Chobanian & Avedisian School of Medicine.

"They've had a neurological catastrophe. So if you want to call them not dead, what does that accomplish? Does that help anybody?" says Greer, who helped write the latest guidelines from the American Academy of Neurology on how doctors declare brain death, affirming the current testing regimen.



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"There has never, ever been a case of a person correctly diagnosed as brain dead where that person has recovered any degree of consciousness," agrees Dr. Robert Truog, a Harvard University professor of bioethics, anesthesiology and pediatrics. "It's really important for the public to understand that."

But the American College of Physicians (ACP) recently issued its own position paper embracing the whole-brain standard.

"The American Academy of Neurology proposes putting into law only three specific criteria for the determination of death by neurologic criteria. ACP opposes putting only three criteria into law because doing so would be overly narrow and privileges certain brain functions over others," says Dr. Matthew DeCamp, an associate professor at the University of Colorado School of Medicine, who helped write the ACP position paper. "The whole-brain standard is a firmer biologic foundation for determining death."

Some doctors and advocates would like to do away with brain death entirely. Others call for additional testing to rule out functioning of the hypothalamus.

"What we really need to do when we have too many false positives on anything in medicine is improve our testing so it gives less false positives," says Dr. Daniel Sulmasy, a bioethicist at Georgetown University.

Changes in the death definition could hurt organ donations

But eliminating brain death or requiring additional testing could significantly reduce the number of people who would be eligible for organ donation at a time when organs for transplantation remain in severely short supply.

"I don't think the [Uniform Determination of Death Act] should be revised. It's working, and revisions I think can only lead to lack of conformity throughout the United States," says Peter Langrock, a Vermont attorney who serves on the Uniform Law Commission. "It's an old Vermont expression: If it's not broke, don't fix it."

One of the reasons the commission paused rewriting the death act was concern that it would result in a hodgepodge of different laws, especially in the current highly polarized political environment and among debates over issues of life and death in the context of abortion.

"It's hard to imagine on how there could be agreement," says Dr. James Bernat, a professor of neurology at the Geisel School of Medicine at Dartmouth. "It could open a Pandora's box."

But others disagree.

"I think it would be much better to bring the law into accord with contemporary clinical practice," says David Magnus, a professor of medicine and bioethics at Stanford University School of Medicine.

Pope, the bioethicist at Mitchell Hamline School of Law, would like to see a federal law or regulations that would create a uniform national standard.

"I always think of it like a bridge. You don't wait until the bridge falls into the river. You try to keep it updated and repair it. Fix the cracks and so forth," Pope says. "We're starting to see cracks. Let's try to fix the problem now before it gets worse."

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