

- [Home](#)
- [About The Author – Steven Novella, MD](#)
- [Topic Suggestions](#)

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[A Case of Brain Death](#)

Published by [Steven Novella](#) under [Neuroscience](#)
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The New Yorker magazine's latest issue features [an article about the sad story of Jahi McMath](#). Jahi was a 13 year old girl who four years ago underwent a routine tonsillectomy to treat severe snoring and breathing problems. Unfortunately the surgery was complicated by severe bleeding post-op, leading eventually to a cardiac arrest. After a sustained effort at resuscitation the doctors did manage to get her heart working, but by that time her brain was severely damaged by lack of oxygen. She was declared clinically brain dead.

This is not where the story ends, however. Since then the family has refused to accept the diagnosis of brain death, prompting a prolonged conflict with the hospital. Eventually Jahi was removed by the family to an undisclosed hospital in New Jersey, and ultimately discharged to home care, where she remains.

I have had several questions about the story, and I will try to add some insight, with the caveat that I have no direct knowledge of the medical facts of the case beyond what is reported in the New Yorker article [and elsewhere](#). I have not examined her, spoken directly to anyone involved in her care, or reviewed medical records. But there is a lot of information in the public domain and I can speak to that information, as far as it is accurate.



There are several layers to this story. There is a legal layer, as the family is suing the hospital for malpractice. I will not address that aspect of the case. There is the neurological layer – what is brain death and is this girl dead? There is also a personal and cultural layer here in terms of the family's reaction. Let me start with some thoughts on this.

I will first say that I completely sympathize with the family. Of course it is horrible and tragic to lose a healthy 13 year-old child to a routine surgical procedure gone horribly wrong. I understand their anger, frustration, and grief. In addition, the family (again, according to public reporting) has lost trust in the hospital and in the system. They are African American and feel that there is an aspect of discrimination in how Jahi was treated. The mother, Nailah, is quoted in the New Yorker article:

Nailah, who worked in contractor sales at Home Depot, said, “No one was listening to us, and I can't prove it, but I really feel in my heart: if Jahi was a little white girl, I feel we would have gotten a little more help and attention.”

This is an extra layer of tragedy in the case – the family was meant to feel as if an element of racism played a part in Jahi's outcome. I have encountered this myself numerous times, sometimes with some legitimacy, but often (from my perspective) when no racism was present. I can't speak to the state of mind of any of the caregivers in Jahi's case. But the reality is that her family lived with enough racism in society that it affected their ability to trust the system.

Allowing your child to go under the knife requires a tremendous amount of trust. Further, medical care can often feel impersonal, and can be intimidating when scary things are happening that you do not fully understand because you are not an expert yourself. When that trust, and that feeling of lack of control, is paired with a horrible outcome, it is natural to feel betrayed.

Those feelings, in the context of a minority family, appears to be driving this case to a significant degree. Now those same doctors are telling the family that Jahi, who looks alive, is actually dead. They don't want to let Jahi down again by trusting those same doctors.

Unfortunately, when there is a critical break down of trust like this in a complex case, we don't really have a good mechanism for resolving any conflict. Doctors and hospitals usually defer to the family as much as possible, giving them time to process their grief, having family meetings, calling in other experts to weigh in, etc. None of this was enough, however. It also seems that the family has dug in their heels, and may now be too invested in their belief that Jahi is alive to let her go.

This leads us back to the neurological layer of this story. The New Yorker article framed their piece as a question – what is the definition of life. There is a legitimate question in there, but I don't think it is actually that controversial outside of certain religious sects.

Obviously, when someone stops breathing and their heart irreversibly stops beating they can be declared dead. For a time, however, the cells in their body are not dead. There is a window when someone may be dead, but it is not necessarily impossible to resuscitate them. Doctors use their judgement when deciding to stop attempts at resuscitation. Part of that judgement is how much brain damage may have resulted from the prolonged arrest. There is no point in getting a heart beating again if the brain is dead or almost dead.

For this reason the medical and legal concept of brain death was developed. You can also declare someone dead even if their heart is beating if a thorough examination clearly indicates that there is zero brain function. Not only the higher parts of the brain, but the brain stem and the brain reflexes must also have no function. You can still have spinal cord reflexes, however, and still be considered brain dead. You can also demonstrate the complete absence of brain wave activity, or the complete absence of blood flow to the brain.

In Jahi's case, a neurological exam specifically designed to test for any flicker of brain activity was consistent with brain death. Further, a blood flow scan showed no blood flow to the brain. She was declared brain dead, and is legally a corpse (to be blunt). That is why the family moved her to New Jersey, which is one of only two states that recognize religious objections to the notion of brain death.

This is where we now get some complexity, although I honestly don't think it changes the situation. Dr. Alan Shewmon got involved with the case – he is a neurologist who objects of ideological and religious grounds to the notion of brain death. He reviewed video of Jahi and concluded there is evidence in the video of brain activity,

therefore she is not dead.

Essentially, Jahi occasionally twitches her fingers or toes. These are almost certainly spinal reflexes, and not inconsistent with brain death. Nailah, her mother, believes that Jahi is responding to verbal commands. She will tell her to move a finger, and then sometime later Jahi will move a finger. If it's not the right finger Nailah will say, "Not that one" until she twitches the correct finger.

This is also very common – family members tend to overinterpret random movements as if they are deliberate. Shewmon believes that the movements are more accurate than can be explained by random chance, but I am doubtful. Further, he may not be accounting for selection bias in the videos he is being shown.

There is good reason to believe that Jahi simply cannot be following verbal commands. The New Yorker reports:

On the scans, Machado observed that Jahi's brain stem was nearly destroyed. The nerve fibres that connect the brain's right and left hemispheres were barely recognizable. But large areas of her cerebrum, which mediates consciousness, language, and voluntary movements, were structurally intact.

There are two things to note here. This study apparently does show some remnant of brain tissue. If there were zero blood flow the brain would be entirely gone by now. So there is likely a small amount of residual blood flow, too little to show up on the prior scan, that is keeping some brain tissue alive. However, that does not mean that this remnant is functioning at all.

But perhaps more important is the fact that the brain stem is "nearly destroyed." The brain stem is necessary for a person to be conscious. Even if your entire cortex were intact and unharmed, without a brain stem you would be in a permanent coma, without the ability to generate wakeful consciousness.

Further, without a brain stem there is no way for auditory signals to get to the brain. Jahi cannot hear, and therefore cannot respond to verbal commands. Therefore the video evidence of her finger twitching is not evidence of consciousness.


There is perhaps a legitimate discussion to be had about whether or not the remnants of brain tissue mean Jahi is truly completely brain dead or not. But in my opinion, this is a distinction without a difference. She is clinically brain dead, and any remnant is irrelevant. She is not aware of her own existence. Without a brain stem she cannot be conscious. It is sad to say, but there is no functional difference from Jahi's perspective between being fully dead and whatever flicker of brain activity may plausibly remain. It is effectively nothing.

The family may be beyond the trust necessary to accept this reality. They also appear to be enabled in their denial by Shewmon, who has an agenda of his own.

Meanwhile millions of health care dollars have been spent maintaining this poor dead girl's body, with no end in sight. The family remains in a limbo of denial. The other child in the family must live in the shadow of their dead sister, who absorbs much of the family's time and resources. Legal expenses are also piling up. The entire saga furthers a narrative of distrust. It is a tragedy from beginning to end.

[30 responses so far](#)


30 thoughts on "A Case of Brain Death"

-  *tb29607* says:
[February 1, 2018 at 10:27 am](#)


Nice summary of a topic lettered with emotional land mines.

I think it is worth mentioning that the blood flow and EEG are confirmatory tests only and this point needs to be explained to parents prior to test. Far too often someone will take the easy path of telling the family that if there is no brain blood flow, the patient is dead, and not address that families often hear this to mean that if there is flow, the patient alive. Finding blood flow, or some residual activity on EEG does not change the diagnosis of brain death.

It is incredibly difficult to help families process brain death in a child and one wrong word by anyone can completely derail the discussion. That cases like Jahi's are so rare speaks well of how they are handled in general. Unfortunately, I think cases like this are inevitable in our our health care system which gives families the final decision.


-  *tb29607* says:
[February 1, 2018 at 10:27 am](#)

littered, not "lettered".

-  *Willy* says:
[February 1, 2018 at 10:49 am](#)

I'd like to ask some questions. From the descriptions above, it sounds like brain tissue is "disappearing" in cases like this. Is this correct? Is the skull becoming an empty cavity? If the tissue is/was dead, why is necrosis not an issue? Why, if the heart is beating, is there no blood flow to the dead brain at present? As I read it, it seems the heart and lungs are functioning without a brain (I see no medical equipment in the photo). Is this correct?

Sorry if these are dumb questions or if I've misinterpreted the article.

-  *MikeB* says:
[February 1, 2018 at 11:20 am](#)

The quotation from Mark 11:24 referred to in the photo is "Therefore I tell you, whatever you ask for in prayer, believe that you have received it, and it will be yours."

Oh, humanity.