

Deciding Whether to Withdraw Care

Mr. Mugler is a 72-year-old male who suffered a massive ischemic stroke three weeks ago affecting large portions of both cerebral hemispheres. He was found unresponsive in his apartment by a neighbor and brought to the emergency department, where he was intubated and admitted to the neurological intensive care unit (neuro ICU). Initial CT imaging showed extensive bilateral infarcts with significant cerebral edema. Despite aggressive medical interventions, Mr. Thompson has shown minimal neurological improvement.

Mr. Mugler has not regained consciousness and shows no purposeful responses to stimuli. His neurological exam reveals only primitive brainstem reflexes, such as a gag reflex and his eyes opening spontaneously, but there is no tracking or response to commands, indicating no purposeful movement. The neurology team has assessed him as being in a persistent vegetative state with minimal likelihood of meaningful cognitive recovery. Multiple neurologists have reviewed his case and concur that even with prolonged supportive care, he is unlikely to regain awareness or the ability to communicate.

Mr. Mugler's body, however, remains relatively stable from a physiological standpoint. His heart is strong, his kidneys function well, and aside from the catastrophic brain injury, his other organ systems are intact. The neuro ICU team has informed his family that he could potentially survive for months or even years with continued life support, but his quality of life would remain severely compromised. For the past four weeks, Mr. Mugler has been kept alive on life-support, including mechanical ventilation to assist him in breathing and receiving artificial hydration and nutrition.

To assist his breathing, Mr. Mugler was intubated using an endotracheal tube which was inserted into his mouth and down his windpipe, allowing for mechanical breathing via a ventilator. He has failed several attempts at extubation, which involves removing the endotracheal tube to see if the patient is able to breath unassisted. Each time, Mr. Mugler was unable to breath on his own and had to be re-intubated. However, an endotracheal tube cannot remain in place indefinitely. For prolonged ventilation, a patient will often undergo surgery to have a tracheostomy performed, in which a surgical opening is created in the neck allowing a permanent breathing tube to be inserted, allowing for easier for long-term ventilation.

Mr. Mugler is also receiving artificial hydration and nutrition through a nasogastric tube (NG tube). An NG tube is thin, flexible tube inserted into the patient's nose and down their throat, into the stomach, allowing providers to deliver food and medications to a patient who is unable to eat by mouth. However, an NG tube can cause irritation and discomfort, so it should not remain

in place for more than a month. For this type of feeding to continue beyond that timeframe, a patient will often undergo surgery to have a percutaneous endoscopic gastrostomy tube (PEG tube) placed, which gets permanently inserted into the stomach through the abdomen.

The initial goal in providing this life-sustaining care was to allow time for neurological testing and recovery, to see if Mr. Mugler's condition would improve over time. Unfortunately, it has become clear that his condition is unlikely to further improve, and that prolonging his life will require him to remain dependent on this level of care for the long-term. Because Mr. Mugler has been intubated for three weeks, the neuro ICU team must soon determine whether to proceed with a tracheostomy (trach) for long-term ventilation and a PEG tube for long-term nutrition, or whether to extubate him and transition to comfort-focused hospice care, which would likely result in his death within hours to days.

Mr. Mugler is divorced and has two adult children in their 40's. His son, Michael, and his daughter, Rebecca. He has no advance directive, no living will, and never explicitly named a healthcare proxy. His ex-wife has not been involved in his care. Prior to his stroke, Mr. Mugler lived alone and was semi-retired, working part-time as a bookkeeper. He was described by his children as fiercely independent, somewhat reclusive, and "not the type to want people fussing over him." He rarely discussed personal matters, including his wishes about medical care.

Michael, who lives locally, has been making medical decisions as the primary next of kin. He firmly believes that his father would not want to live in this condition. Michael recalls his father once saying, after watching a news story about a woman in a persistent vegetative state, "If I'm ever like that, just let me go. That's no way to live." Michael has been advocating strongly for comfort care only, arguing that maintaining his father on life support long-term would violate everything his father valued about being independent. He has requested that the team not proceed with the trach or PEG tube, and instead extubate and provide comfort measures.

Rebecca, who flew in from across the country, vehemently disagrees. She argues that while their father valued independence when he was healthy, he also fought through difficult times in his life and "never gave up on anything." She believes that proceeding with the trach and PEG tube will keep their father's options open, saying "where there's life, there's hope." Rebecca also points out that their father never put his wishes in writing, so they can't be completely sure of their dad's wishes either way, and explains that she's just trying to do right by him by giving him a chance.

Legally, both children have equal standing as next of kin. The hospital legal team has indicated that without consensus, the hospital may need to seek a court-appointed guardian to make decisions, a process that could take weeks or months. Neither Michael nor Rebecca want to escalate things to a court decision, and indicate that they hope they can reach some sort of

consensus, but feel that they need more guidance from the healthcare team in determining what would be best for their father.

The attending physician in the neuro ICU tells them that she understands why some families choose to continue with long-term care in these situations, because withdrawing care can feel like "giving up" on their loved one. However, she also notes that in her experience, families who chose to move forward with a trach and PEG tube often experience prolonged grief and moral distress, visiting their loved one in a nursing home for months or years while the patient remains unresponsive. She then tells them that no matter what they decide, their father will need to be moved out of the neuro ICU within the next week, because his ICU bed is needed for other critically ill patients given that his care can now be managed in either a long-term acute care facility or through hospice services.

Still, the only thing Michael and Rebecca can seem to agree on is the fact that they both want to do what is in the best interest of their father. The neuro ICU team finally suggests that they request an ethics consultation, in order to get another perspective on what course of action is most likely to promote the well-being of Mr. Mugler. Happy to have more guidance, Michael and Rebecca agree to this meeting, and both commit to going along with whatever course of action the ethics committee recommends.