

PERSPECTIVE

Death by Ableism

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In June 2020, Michael Hickson of Austin, Texas, was admitted to a local hospital because of complications related to Covid-19. Mr. Hickson, who was 46 years old, had substantial verbal, cognitive, and mobility limitations resulting from an anoxic brain injury caused by a myocardial in-

farction he'd had several years earlier. Mr. Hickson's medical team decided not to treat his Covid-19 complications. In a recorded conversation with Mr. Hickson's wife, a physician stated that because the patient could not walk or talk, he had no quality of life. Since treating his

Covid-19 symptoms would not change his functional status or quality of life, the team decided to withdraw care and nutritional support.¹ Mr. Hickson died several days later.

His death captured media attention and shook the disability community. As I read Mr. Hick-

son's story and listened to the conversation posted online, I wept. I wept for Mr. Hickson. I wept for his family. And I wept for my family.

Throughout most of my childhood, my Uncle David lived within a 20-minute walk from our home. He was social, spending hours walking the neighborhood, striking up conversations, and keeping up with the neighborhood gossip. He loved telling corny dad jokes, listening to country music, playing gin rummy, and watching reruns of 1950s sitcoms. For my birthday each year, he would give me a card signed in his shaky cursive: "Love, Uncle David."

David lived with my grandparents and had a developmental disability that included intractable seizures. Several epilepsy surgeries combined with high daily doses of antiepileptics limited his seizures to several per week. His seizures were a family fixture and occurred more frequently when he was excited, such as during the holidays. One Christmas when he had a seizure at the dinner table, we were all amused at the serendipity of his having chosen to sit in a chair with wheels. We easily rolled him away to his bedroom for his post-seizure sleep while we finished the meal. As David entered mid-life, his seizures became more frequent, resulting in more falls, which led to several traumatic brain injuries. Although he always recovered, he lost a bit more function each time. Owing to my grandparents' aging and his increasing needs, David moved into a nursing home.

On December 23, 2016, at 54 years of age, David was admitted to the hospital for aspiration pneumonia, which had most likely re-

sulted from a seizure. My parents and I rushed to meet David in the emergency room. My grandparents, now in their 90s with poor hearing, relied on us to advocate for David and communicate with the medical team.

David was incredibly weak and had difficulty swallowing. As a certified speech-language pathologist, I, along with the team, monitored his swallowing abilities. Though his strength and swallowing improved each day, he remained NPO. Four days after he was admitted, David no longer needed medical treatment for pneumonia. The hospital team decided to discharge him. Unfortunately, David was still unable to swallow safely. The team looked to us to determine how to proceed.

We had always expected that David would have a reduced lifespan because of the devastating effects of his seizures and resulting injuries. Yet he had proved to be remarkably resilient, repeatedly and unexpectedly recovering from injuries and illnesses more severe than what he was facing now. We were unsure whether this was the end.

Believing that a G-tube was too invasive, we proposed that David be discharged with a several-day trial of an NG-tube. It was now December 27, and David's neurologist and other regular clinicians could not be reached. An NG-tube would buy him a few more days until his team could weigh in, and in the meantime we could see whether his swallowing abilities continued to improve. During a previous hospitalization, David had tolerated an NG-tube well and had been successfully transitioned to a full oral diet. We knew that an NG-tube would not necessarily protect him from additional aspiration,² but

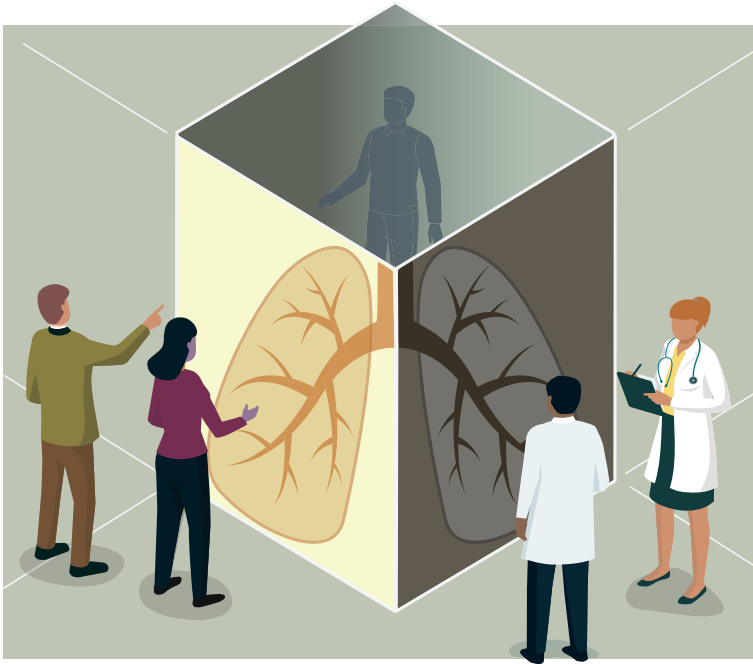
we also knew that eating by mouth would lead to pneumonia and probably death.

The hospital team resisted. They argued that an NG-tube was "uncomfortable" and that it was inhumane to subject David to any potential pain. Instead, they recommended that David be placed in hospice care with no nutritional support. We pleaded with the team to authorize a trial of the NG-tube, and we believed we'd reached an agreement with them before we went home for the evening.

The next day, as my parents and I were preparing to visit David, we were informed that he had been discharged without an NG-tube and with instructions for a full oral diet. The hospital team had previously called my grandparents, David's legal guardians, to inform them of the plan and obtain their consent. To this day, we remain uncertain whether my grandparents understood what they were consenting to.

As anticipated, within a day David developed aspiration pneumonia. Again, the team pressed us to admit him to hospice. This time, we relented. In the early evening of New Year's Eve, I sat with David for the last time. I used suction and a sponge to clear the copious amount of secretions that had filled his lungs and poured from his mouth like quickly moving lava. As I worked silently, tears streaming down my face, I hoped I was providing some comfort in David's last moments and that he understood why we'd agreed to hospice. After several hours, he died.

For months, I could barely sleep. Whenever I closed my eyes, I saw David's face as it had looked during his final hours — struggling to breathe, his wide-



open eyes seeming to implore, “Why would you allow this to happen?” My parents and I were plagued by questions: Had we made the right decision? Should we have fought for him to be treated again for pneumonia? Had it really been his time to go? David had needed us to advocate for him. Had we failed? To this day, I struggle to talk about what happened.

The medical team recommended treatment that they believed was in David’s best interest. They believed his quality of life was so low that a minor, minimally invasive intervention was too burdensome. That belief was steeped in unwitting ableism — the notion that the life of a person with a disability has less value than the life of a person without a disability.

Throughout his life, David constantly faced ableist biases. Seeing a diagnosis of “developmental disability,” medical teams would incorrectly assume he was nonverbal, incontinent, and unable to ambulate independently. I

once posted signs in his hospital room listing his favorite discussion topics, such as country music and recently released comedic movies, hoping that if we humanized him, his team would provide better care.

At the start of the pandemic, the possibility that there would be insufficient health care resources to meet the medical need caused widespread panic. Previously closed-door conversations about medical rationing became public discourse. Eight U.S. states had delineated crisis standards of care that deprioritized persons with “low quality of life” and those with diagnoses that are highly correlated with disability.³ Although the Department of Health and Human Services stated that these plans violated the Americans with Disabilities Act,⁴ medical teams still made individual-level decisions about who should and should not be treated. They made decisions similar to those of David’s team, now with the added rationale that the pandemic was stretching health

care resources. It seems clear that such rampant ableism, and its profound consequences, will continue unless systemic changes are made.

On January 1, 2017, my parents and I packed David’s belongings into several small boxes. Mixed in with the boxed sets of DVDs and the old greeting cards, I found a stack of a dozen pastel-colored index cards, each with an affirmation written on it. When I asked my dad about the cards, he said that years of being ignored and underestimated had weighed on David, who had occasionally struggled with feelings of worthlessness. The cards, with statements about his importance to his family and community and his positive attributes, such as his sense of humor, reminded him of his worth. As I read the words on the cards, I prayed that at the end David knew he was valued.

Disclosure forms provided by the author are available at NEJM.org.

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