

## PERSONAL NARRATIVE

### The Role of Hope, Compassion, and Uncertainty in Physicians' Reluctance to Initiate Palliative Care

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#### Abstract

This article addresses whether physicians' close ties to their patients might play an unexamined role in their reluctance to initiate palliative care. In cases characterized by uncertainty, physicians' emotional investment in their patients and patients' families might unduly promote decisions to continue aggressive treatment rather than transition to comfort care. Continued evaluation and communication of patient status, including scheduled objective consultations, can align compassionate actions with patients' best interests. This argument and analysis are based on a case of new onset refractory status epilepticus (NORSE).

#### A Recommendation to Withdraw Treatment at the Eleventh Hour

When my son Daniel, age 22, was struck by prolonged seizures in September 2013, he was sent to one of the finest US hospitals and cared for by a skilled and devoted medical staff. After 78 days in a medically induced coma, Daniel died. My family and Daniel's medical teams were devastated. Only after reading his autopsy report—which found extensive, global brain damage—and thinking back to Daniel's last days did I begin to realize that the fight to save his life went on too long.

In the last weeks of his life, Daniel's abdomen was sliced open to clean the aftermath of a displaced feeding tube. His bedsores grew; he had blood clots, kidney failure, and sepsis. His body was distorted by hydration, diuresis, and rehydration. He was ravaged by tubes in orifices both natural and surgically created. Until the last two days of his life, my family and I believed Daniel would walk out of that hospital the same person he was before. No one told us otherwise.

Daniel's diagnosis and prognosis were not discussed during our first 3 formal conferences with his epilepsy and intensive care unit (ICU) teams. The focus was on the crisis of the moment—the next test, drug modification, or procedure. It was only at the fourth and final conference that Daniel's prognosis was abruptly summarized for us. His physicians finally spoke to us in one voice to recommend we [discontinue aggressive treatment](#) the day before he died.

The catalyst for their abrupt, unified recommendation to stop treatment was an epilepsy physician who had never seen Daniel before. She was covering for a colleague on his epilepsy team who was about to attend a 5-day conference. After reviewing Daniel's records, she asked my husband and me gently, "Did anyone ever talk to you about function?" She left us to confer with her ICU colleagues. Her question reverberated throughout Daniel's teams. The next day, Daniel's ICU and epilepsy physicians assembled before us to give their recommendation to stop aggressive treatment. They believed it unlikely Daniel would survive. If he did, he would probably not be able to make new memories, recall old ones, speak, or move. He would suffer unremitting seizures.

The physicians were haggard and miserable; one was weeping. My husband and I were dumbfounded. My husband rejected their assessment since Daniel's first two brain magnetic resonance images (MRIs) were normal and unremarkable. The third suggested only small signs of brain atrophy. This atrophy caused concern in an epilepsy fellow, but an ICU attending physician with a neurology background was not worried. We chose to believe the more optimistic view of the senior physician and never asked for anyone else's. We didn't want to look for bad news. At that last conference, my husband insisted on a new MRI since weeks had passed since the last one. Confronted with their unified recommendation and the final MRI that suggested global, extensive brain atrophy, we decided to stop aggressive treatment. The next morning, Daniel died less than one hour after we stopped aggressive treatment.

It has taken me a few years to think beyond the pain of my son's death. I now question why Daniel's physicians waited so long to tell us that the quality of his life upon his unlikely survival would be questionable and that his death was imminent. Ongoing communication of his status would have given us time to think and to discuss with his physicians how Daniel, my husband, and I valued life and viewed death. I considered the possible explanations for the physicians' silence: they didn't know his prognosis, they knew but they were too busy to involve themselves in end-of-life discussions, and they didn't care enough about him or us to say.

I immediately rejected the last two explanations. His physicians were very involved in Daniel's case. They cared deeply about Daniel and about us. With perspective that only hindsight can give, I believe it was the uncertainty that pervaded his illness—combined with their compassion—that made Daniel's physicians reluctant to initiate end-of-life discussions.

### **NORSE: A Worst-Case Scenario for Communication**

One ICU physician told me a few weeks after Daniel's admission that she thought Daniel had new onset refractory status epilepticus, commonly referred to by its acronym NORSE. But she abruptly left Daniel's team due to her own illness before she communicated that diagnosis to others. When I asked one of Daniel's epilepsy physicians

if Daniel had NORSE, he was reluctant to give any formal diagnosis. The diagnosis of NORSE was confirmed only indirectly after Daniel's death, when one of his epilepsy physicians referred me to other physicians investigating NORSE. When speaking with Daniel's medical teams after this confirmation, I learned that some members of his ICU team had never heard of the term NORSE.

Physicians currently have an incomplete understanding of NORSE, and their understanding was even more deficient when my son was hospitalized almost 5 years ago. It is easy to jump to conclusions about the physicians' behavior without understanding the pervasive uncertainty that characterized Daniel's case and NORSE cases today. A proposed consensus definition for NORSE was published only in April 2018. The international group of experts stated: "NORSE is a *clinical presentation*, not a specific diagnosis, in a patient without active epilepsy or other preexisting relevant neurological disorder, with new onset of refractory status epilepticus without a clear acute or active structural, toxic or metabolic cause."<sup>1</sup> Recent reviews find no confirmed etiology in more than half the cases of NORSE and no established effective treatment protocol. Cases that remain cryptogenic often result in significant brain damage and death.<sup>2,3</sup> A common lexicon for NORSE is just beginning to coalesce, although the term NORSE was first posed in 2005 to describe the syndrome of sudden seizures in healthy people that results in "catastrophic outcome."<sup>4</sup>

The hospital rotation schedule and organizational structure further impaired physicians' understanding and communication of Daniel's condition. In Daniel's case, there was a division of responsibility by specialty: the epilepsy team focused on his brain, the ICU team, on his body. The two teams saw him at different times of the day. Other specialists from cardiology, neurology, infectious diseases, and nephrology consulted, creating many separate opinions. There was no single physician responsible for integrating these [silos of information](#) from the various specialties. The uncertainties of NORSE were compounded by the lack of integration of the information that did exist.

When Daniel was first admitted to the ICU, it seemed no one knew what was happening to him. As time progressed and all tests returned negative, Daniel's physicians understood more about his condition by learning the diagnoses that had been eliminated and the complications that had accrued. Even without consensus terms or a body of evidence for NORSE, physicians developed their own expectations for Daniel's outcome. Because communication among them was not integrated, each physician's understanding was incomplete. And because the physicians did not apprise us of their changing prognoses, my husband and I were the least informed.

### **Hope as a Humane Response to Uncertainty**

No one wanted to predict devastating brain injury without certainty, which no procedure can guarantee. No one wanted to make the call to stop aggressive treatment without

clear evidence such treatment would be futile. The only certainty was that any deviation from aggressive treatment of NORSE would likely result in worse outcomes, including greater likelihood of death. Hope grew in this void left by uncertainty, a hope based on emotion since there were so few facts. And no one wanted to quash hope when hope was the only good thing that remained.

Daniel's physicians and nurses fought to save his life. They stayed beyond their shifts. They checked on him while on different rotations and even on their days off. Their devotion was profound. The staff never spoke to Daniel directly. He was initially unresponsive upon admission to the hospital and then placed in a medically induced coma to stop his seizures, a common treatment for NORSE. Perhaps the staff could not resist our endless, unspoken plea to save our son. Perhaps the sight of him lying there so vulnerable and beautiful in his youth compelled the physicians to action.

The medical teams' emotional investment in Daniel and in us might have led his physicians to believe Daniel must live not only for Daniel's sake but also for ours—and perhaps for theirs as well. Everyone desperately wanted Daniel to live. Almost no one focused on what his life would be like when he survived. It took the covering physician with no emotional tie to us to jolt Daniel's physicians into reassessing his condition. Compelling evidence to support the recommendation to withdraw aggressive treatment must have existed in his records—and who knows for how long. Because when Daniel's teams did reassess his condition, they quickly concluded that aggressive treatment should end.

The hope and compassion that fueled the medical teams' drive to save my son is what makes medicine humane. Without compassion, medicine is heartless. But compassion needs checks and balances.

### **Recommendations to Balance Hope and Action**

NORSE is not the only acute illness characterized by uncertainty. In cases of [uncertain diagnosis](#) and prognosis, there must be one person responsible for integrating the silos of information from various specialists and teams. What remains unknown among some staff members should be articulated. The physician overseeing the unit where the patient spends the most time can be the leader who gathers the medical teams and family together as one decision-making unit to ask, What should we hope for, given what we know and expect? Discussions should be held as soon as the situation is deemed highly unpredictable, life-threatening, or grievously life-changing so that families have time to think and plan. The formal inclusion of an objective assessment can counterbalance the emotional involvement of the staff. Without complete information, physicians and families might hope for and work towards a recovery that is not possible and thereby delay end-of-life decisions.

Periodic and candid discussions of the relevant knowns and unknowns in a given case would help the medical teams and the family navigate the murky waters together. Only with eyes and hearts wide open can physicians and families align care to the changing best interests of the patient.

## References

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