

*This is a resident case log of a patient encounter in which an “Aware Medicine topic” was central.*

### The Slippery Slope Between Hope and False Hope

Mr. B was an 84 year old man whose function had been declining quite rapidly over the past 6 months to the point where he had difficulty walking and coughing. He was admitted to an outside psychiatric hospital for a work-up with Lewy Body dementia high on the differential. During that admission he had an episode of decreased responsiveness, thought to be over sedation due to anti-psychotics, causing him to aspirate, develop respiratory distress, and be intubated. He was then transferred to our unit.

We faced many challenges with Mr. B. Our first challenge was medical. For months prior to his initial hospitalization, he was transferred from the home of one family member to another so that each one knew him at a different stage of his decline. They could not come to a consensus of his baseline status. Since his baseline neurological status, the reason for his rapid decline prior to admission, and the exact cause of his decreased level of consciousness at the outside hospital was not known, we could not know how he would handle extubation from a neurological standpoint. We also could not be certain about the reason for his respiratory failure. We knew he had aspiration pneumonia based on the history and clinical picture and were treating it, but he also had bilateral pleural effusions and significant right ventricular hypertrophy.

Our other challenge was conveying to the family the seriousness of his illness while acknowledging that we didn't have all the medical answers. One thing the family was in agreement about from the beginning was that Mr. B would never have wanted to be on life support. What that meant in terms of his code status was entirely unclear.

On admission to our hospital he had been full code and for over a week he had been improving very little clinically despite our treatment of his pneumonia and adjustments to his ventilator settings. The attending on service that week had made it very clear to the family on the first day of his admission that since there were many unknowns in his case we would be aggressive in his management with hopes of extubating him and then continuing the work-up of his dementia and his cardiac function. Despite over a week of little to no improvement, the family was holding on to this hope and had not changed his code status even though they knew he probably would not want to be ventilator dependent.

An event on one of my call nights brought to the forefront the struggles the family faced regarding his code status. One night, even with soft limb restraints, he self-extubated. I spoke with the family and summarized that despite our aggressive treatment, he was not improving and that this might be a good time for them to re-assess what they believe he would have wanted in this situation. We would closely monitor his respiratory status and they could decide, if they chose, to not re-intubate. After a brief discussion, they chose to reintubate if necessary. For the one hour he remained extubated, they were quite persistent in attending to his comfort and repeatedly asked the nursing staff to make small adjustments such as bringing warmer blankets and moving the nasal cannula tubing so that it did not bend his ear. Yet, when we re-intubated they asked that we tie his restraints tighter and sedate him more heavily so that he would not self-extubate again.

I understood the family's struggle since I, too, was conflicted about the right approach to M. B's care. Mr. B had made it clear to his family that he would not want to have his life sustained and the stories his family told about him as a fiercely independent man who avoided doctors and hospitals confirmed this. By now he had been intubated for over a week with no significant improvement and even prior to his hospitalization he had been deteriorating quickly and steadily. It didn't seem as if he

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would recover. The family was holding out for hope as any caring family would, but at the same time was prolonging his suffering by subjecting him to treatment he most likely would have rejected had he been able to do so.

I wondered if the hope that the medical team had given them was more than we had anticipated. It felt to me that the patient’s wishes were neglected by his family who wanted to keep their father alive. This conflict between hope and No Code continued until a half hour before his death. He was extubated after a successful spontaneous breathing trial one morning, but was developing respiratory failure throughout the day. Seeing his grave prognosis, the family finally decided to make him DNR/DNI, but after talking with the attending decided to continue aggressive management without officially transitioning to comfort care orders. An hour before his death, I talked with the family about alleviating his air hunger with continuous morphine and he was visited by hospice a half hour prior to his death. It was apparent that the nursing staff had hoped he would become a “No code” days before he actually was.

On the positive side, we were honest with the family about what we did not know medically, but could have better conveyed that his prognosis was not favorable. I feel that had we had a better discussion of code status at admission, we could have better managed his care in line with his and his family’s wishes. Maybe we could also have come up with a plan that limited the number of days of aggressive treatment with no significant clinical improvement before making him DNR/DNI. Ideally, I would have liked the family to have decided sooner so that he would not have had to be intubated for so long and been able to die under the care of hospice in a floor bed. However, if the family wasn’t yet ready for this, I would absolutely not have wanted them to live with regret in their hearts that did not what they should have done for their father.

From this experience I will take with me the importance of discussing code status with the family as well as taking more time to understand their thoughts and struggles in this process. It’s our job to help the family make an informed decision that is best for them in the care of their loved one and then to support that decision. One concrete thing I would have done differently was to discuss my thoughts with the attending and nursing staff earlier so that at least we all were on the same page.