

# Extubation Take Two



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JOE\* WAS A young teen with severe nonverbal autism spectrum disorder (ASD) who arrived to our PICU late one evening from a community emergency department for ongoing treatment of status epilepticus and subsequent respiratory failure. Earlier in the day, he was up and playing, acting normally, when he suddenly began having a violent, generalized tonic-clonic seizure. Terrified, his mom called 911 and he was brought to a local emergency department. He was rushed into a patient room and quickly intubated due to respiratory failure. Over the next hour, due to swift care from the medical team, his seizures stopped. However, because he was slow to wake up, our team was notified and he was transported via helicopter to our PICU for ongoing care.

When Joe arrived on the stretcher, we noticed how calm and comfortable he appeared to be. Our transport team had stated that he was starting to move and reach for the endotracheal tube, so they gave him additional sedation to ensure a safe flight. Mom stood next to Joe, holding his hands with a worried look on her face. I took the lead and discussed the events of the evening and the plan for the night, “. . .and once he wakes up and starts to follow commands, we’ll take the tube out. I think he will do well since he is healthy aside for this seizure!”

Mom paused, fidgeting with the edge of her shirt, looking down, she whispered, “Joe has autism and I am just really worried about what he is going to do when it’s time to remove the tube. You’re going to need a lot of people to control him.” Slightly taken aback, I asked her to elaborate. “Well, you see, Joe doesn’t speak. He hates touch, he hates sound. When he gets worked up, he will become like the Hulk!”

I smiled at mom, with the imagery of this green, angry giant in my mind. “Is there something that we can do to help?”

“Well, I guess he likes hip hop music” she responded.

Chuckling, I muttered, “Well I think that may be a little over stimulating in this situation, huh!”

As expected, Joe began waking up within the next few hours and began demonstrating that he would do well extubated. We performed our usual extubation readiness tests and checked off all of the usual boxes that would typically predict success: he was passing spontaneous breathing trials, he was becoming more neurologically

appropriate, and his secretions were minimal. We had our equipment available for peri-extubation transition, including a nasal cannula, a suction catheter, the pulse oximeter placed on the opposite arm as his blood pressure cuff, set to check his blood pressure every 5 minutes. From our standpoint, we were ready for Joe to soar postextubation. We even had a special safety bed available for children who are more active.

At the time of the extubation, we confidently walked into his room, turned on all of the lights and the respiratory therapist and the bedside nurse hurriedly organized their equipment. Joe’s eyes were open, but he appeared comfortable. The tube was removed, and Joe’s face changed from comfortable to progressively more stunned. Although initially breathing comfortably, as the moments passed, his face became more contorted with panic. With the panic came attempts to roll out of the bed, and with the thrashing came stridor and hypoxia.

Jumping to action, his well-meaning bedside team attempted to apply, and reapply, supplemental oxygen, holding his hand to avoid him from tearing the cannula off his face and tensely stating, “It’s ok, buddy! You are fine!”

“I’m just trying to make you feel better, take some deep breaths, ok?” said another.

The noise level in the room all of a sudden felt deafening, as if the monitors and the supportive phrases were in competition with one another to make the most impact. Joe was throwing all of his heavy, teenage extremities around, and expressing his fear by grunting and crying. This chaotic struggle lasted for only a few minutes until his progressive agitation and evolving respiratory failure impeded his ability to protect his airway, necessitating his reintubation.

Walking down the hallway, I was racking my brain on how I would tell his mother what had happened. I was embarrassed that I had so fully underestimated his needs, I heard his mom expressing concerns and I had this false sense of confidence that I knew what would be best for him. I found her sitting by the windows at the end of the unit, the soft glow of the moon cascading over the walls. “He didn’t do well, huh?” she stated matter-of-factly.

“No, I’m so sorry. I failed to hear your concerns, and for that I am wrong. I did not appreciate how stimulating

the things we do to help children can be, especially for your son. Can we talk about tonight, and how we can do things differently the next time we remove the breathing tube?"

As we all gathered for a family team discussion, I knew that I had failed Joe and his mom by my own biases. From the first day of medical school, it was driven into us that although our focus is treating pathology, the overarching goal of our job is to care for the patient in front of us, a person with specific and unique needs, interests and goals. Sometimes these are simply interesting details, but at times, as was the case with Joe, these details can greatly influence the outcome of their medical management and course. Somehow, somewhere along my training, I had forgotten this critical point. In our meeting, we asked mom targeted questions focused on domains of his personality and needs. And this time, I made sure that I actually listened. Mom reiterated Joe's dislike of loud noise, and fear of being touched by strangers. "He gets very anxious when surrounded by a lot of people or when he is in a new place." She admitted to being overwhelmed when Joe was admitted, and that made me realize that my simply asking her, "How can we help?" was too broad, too open-ended.

"What does he like? And is there anything that he uses at home that calms him down when he is anxious?" I asked.

"A weighted blanket. He loves his camouflage weighted blanket!" Mom revealed. "Oh, and he can use his tablet to speak." And with that, again, it struck me how I have wrongly made assumptions on his ability to communicate or comprehend based on him being nonverbal.

Armed with our new knowledge and action plan, we proceeded to attempt extubation the next day. Given his sound sensitivity, we prioritized having a quiet room with minimal redundant verbal communication. We selected 1 person as the dedicated speaker and encouraged the remainder of the team to utilize nonverbal gestures as much as safely possible. We had his weighted blanket on standby. Additionally, his communication tablet was readily available for his use postextubation. With his history of being easily anxious, we also started him on a low dose dexmedetomidine drip and gave him a single dose of ketamine to help him through the periextubation phase.

At the time of extubation, Joe was alert and comfortable. His mother had a dedicated spot at the side of the bed and the entire procedure was performed in the semi-darkened room in complete silence. Although tensions were high among everyone, there was a palpable air of calm throughout the room, which was in stark contrast to the prior chaotic attempt. He was successfully extubated and the dexmedetomidine drip was slowly titrated off

within the hour. We kept the door partially closed to minimize environmental noise from the rest of the unit but to still allow for patient monitoring. Once he was stable from a respiratory standpoint, we were able to transfer him to the general pediatric floor for ongoing management. Joe rolled out of our unit in his bed, tablet in hand under the security of his weighted blanket, with his tailored sensory care plan firmly attached to his chart.

Aside from his second extubation being a success, one of the most striking aspects of this encounter was how Joe perceived this experience. As he is nonverbal at baseline, we were unable to hear his experience firsthand, and although he uses a communicative device, it was limited to basic commands and responses. Based on our observation of his facial expressions and body language, the difference between the 2 attempts was drastic. With the first attempt, he was crying, moaning, thrashing about, and appeared to be scared. The second attempt was vastly different: he was calm and never once screamed or cried under his weighted blanket, with his mom close by. We also realized that although he did not use his communication device, having it there was our message to him that his "voice" was important to us.

From this experience we learned the importance of listening carefully to parents and our patients, and to actually *hear* them. On hindsight, Joe mom's comment on him being a Hulk should have triggered more of a response from us, and a more in-depth dialogue on the implications of that comment. Our dismissal of her Hulk or hip-hop music comment exposed our inherent biases on what we felt were important for the care of our patients. Perhaps playing hip-hop music in the background softly would have made a difference in the first attempt. Dr. Banner after all becomes Hulk when he is overwhelmed. We learned that individualized and intentional steps must be taken at all times, especially while providing intensive care. Joe taught us that in our attention to the details of the disease process and the procedural norms and protocols, we must consider the totality of our patients. Our care must be centered around their core values, and we must meet them where they are at functionally and developmentally, in addition to their physiologic needs.

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