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Right Brain: Breathe

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It is late in the evening, yet the dawn of my night shift. The nurse pages me with concern, taking me away from all the admissions, discharges, family updates, pages, and orders that routinely fill the night of a PGY-2 neurology resident. I enter the patient's dark, quiet room. She has progressive neuromuscular respiratory failure and her wishes had been clear: Do Not Intubate.

With one glance at my patient, I can see why the nurse is alarmed. It takes me back to my first rotation as a medical student in pediatrics when I admitted a 7-year-old boy with an asthma exacerbation. *Breathe*. I was fixated on obtaining an orderly history from the mother and I did not even look at the child when I walked in the room. On the other hand, the pediatrics senior resident called the pediatric ICU after she had only eyeballed the patient, quickly judging him too sick for the ward. That was my most formative moment of medical school, realizing the clinical judgment between "sick" and "not sick." Now, I see with little formal history required that my patient tonight is quite sick and that we will head into an unplanned end-of-life conversation.

My steps are slow and purposeful. *Breathe*. I first hold the patient's hand, then shake her husband's. I double check her name on her wristband before saying it. I briefly examine her. She is taking agonal breaths and is nearly comatose. What I'm sure was once vibrant brown hair is matted and tangled on the pillow. Her skin, too youthful for death, is ashen and cool.

She was just admitted from the emergency department to the neurology floor after several days of decline at home and was unable to tolerate non-invasive ventilation. She had hope of finding some reversible

cause for the acute decline, such as an infection or metabolic disturbance. From the calmness of her husband, I guessed that I was the first one tonight to break bad news. *Breathe.*

I assess his view of the situation. He thinks she is sleeping. He is waiting for her to wake up and *breathe* better. I pull up a chair close to him. Two nurses join in from across the dimly lit room. We sit 90 degrees apart, knee-to-knee, facing his wife. I lean forward, elbows gently resting on my knees, hands loosely clasped. My voice is soft, but my tone is confident...at least, I think it is, but I am not sure. How do I strike the right balance of confidence with compassion?

I was taught non-verbal language is an important part of family meetings. I tell him the prognosis. I fear she only has hours to days. Where did I come up with that estimate? Then I listen for non-verbal language from him: he *breathes*. I sense initially a natural response of denial, then erupting grief permeates his faltering voice. I sit up a little straighter, turning towards him with my elbow on the armrest. I look at him, and I look at her with him. They say to allow ample silence. I stay quiet. *Breathe.* What is the right formula of silence and guidance?

Despite her shallow, irregular breaths begging to cease, I feel he needs more time. I ask for a stat blood gas, and I promise I will come back within twenty minutes. Perhaps his understanding will be solidified with data, numbers.

pH 7.05, CO<sub>2</sub> 120. I sit down close again. I'm sorry, I say. His gaze is low, but he holds his head up tall. He wishes for her to go home. With much compassion I say that she may die here. He remains stoic but his voice is quivering with each breath. I'm so sorry. He nods. We will make her comfortable here.

As delicate, raw, and important this conversation was, the outcome had been pre-defined by her advance directive in living with Amyotrophic Lateral Sclerosis. I think about the patient and her husband frequently. How different would our night have been if those wishes had not been delineated ahead of time? The burden of the decision had been lifted off of his shoulders- had it also been lifted off of mine? Would I still have been the appropriate person as a PGY-2 resident to hold that discussion? If so, how would I properly prognosticate after having only the experience of a handful of patients? Is the discussion surrounding end-of-life learned by the see one, do one, teach one method? Is it learned in the classroom? Is there a better way to integrate this vital component of neurology practice into our training?

Inevitably, neurology residents will encounter goals of care and end of life conversations. Discussions about end of life are preferable in a calm environment, such as in the clinic with the physician who has known the patient best. However, in many cases, the discussion is triggered by a crisis situation and held in the hospital setting. Regardless of location, these discussions are unique to each patient, and not necessarily straightforward [1]. In theory, end of life discussions are held by experienced physicians who are appropriately trained in communicating bad news and prognosticating [1].

The American Council for Graduate Medical Education (ACGME) requires neurology residents to demonstrate knowledge of palliative care; despite this, formal training is lacking in most neurology residency programs [2]. In a 2007-2008 survey of 338 neurology residents across 34 programs, most

participants (181) reported they had no palliative care training and were found to have poor knowledge in multiple areas of neuro-palliative care [2].

A 2019 study of Stanford University's neurology residency program identified three domains that were barriers to goals of care communication for residents: patient, resident, and systems factors [3]. Patient factors pertained to the complexity of neurologically ill patients, including loss of cognition, language, and physical abilities, any and all of which make decision making and communication about prognosis difficult. Resident factors included uncertainty about patient outcomes, due to resident inexperience and uncertainty in the natural course of neurologic disease. Lastly, systems factors were implicated, especially lack of feedback and supervision. Residents sought experience leading goals of care discussions with attending feedback, but were frustrated by lack of opportunity to do so. In Mehta et al's review of 49 programs, common barriers from the program leadership perspective were lack of time for teaching, availability of faculty, and faculty expertise [4].

Programs report they use formal didactics (lectures, small group discussions) to teach palliative care, but they also reported that this is the least effective method of delivery [3]. Other strategies included standardized patients, case simulations, and use of standardized teaching materials. The most effective methods identified were those with experiential learning (elective and/or required rotations with the palliative care service, standardized patients) [3].

Neurologists should become comfortable and competent in key elements of palliative care, including communication, prognostication, and discussions surrounding withdrawal of life-sustaining measures. One solution is that residents should be active participants in leading these discussions with their patients whenever possible with encouragement, guidance, supervision, and direct feedback of the fellow and/or attending physician. Experiential learning is the most effective strategy; thus, having appropriate fellow/attending supervision in trainee-led family meetings is one way to improve the quality of palliative care training and ensure that every neurology resident has the opportunity to develop these essential skills.

Even though our paths crossed only shortly, this patient and her husband in that somber hospital room stay vividly in my memory. Learning from these delicate moments, a humbling experience among the admissions, discharges, orders, pages, and orders, is essential for growth as a physician.

## References

- [1] Connolly S, Galvin M, Hardiman O. End-of-life management in patients with amyotrophic lateral sclerosis. *Lancet Neurol.* 2015;14(4):435-42.
- [2] Creutzfeldt CJ, Gooley T, Walker M. Are neurology residents prepared to deal with dying patients?. *Arch Neurol.* 2009;66(11):1427-8.
- [3] Goyal T, Hasty BN, Berekyei merrell S, Gold CA. Education Research: Understanding barriers to goals of care communication for neurology trainees. *Neurology.* 2019;93(8):362-366.
- [4] Mehta AK, Najjar S, May N, Shah B, Blackhall L. A Needs Assessment of Palliative Care Education among the United States Adult Neurology Residency Programs. *J Palliat Med.* 2018;21(10):1448-1457.

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