Michael Babcock, Class of 2019

A 25-year-old man with severe cognitive deterioration and memory loss due to autoimmune encephalitis comes in for his follow up neurology appointment. He has a blank look on his face, jaw slightly ajar. I reach out my hand to shake his, but he just stares. His parents tell me about their only son: five years ago he was completely healthy, working on his bachelor's degree in mechanical engineering. Then he began to have seizures, memory loss, and within a year was unable to take care of himself, dropping out of school and moving back into his parents' house. After an extensive neurologic workup, he was found to have a rare autoimmune encephalitis. Apparently he was bitten on the leg by a bug about a month before onset of symptoms, raising the possibility of a causative molecular-mimicry event - the idea being that the immune system mistakes one of the body's own proteins for a foreign protein introduced by the bug bite, resulting in an autoimmune response.

His condition has been stable for the past 2 years. He has marked poverty of speech, sometimes responding with 'yes' or 'no' and rarely, short phrases, such as "I like to cook." His parents tell me that not only is he unable to cook, he needs help with even the basic activities of daily living, such as bathing and dressing. His father starts to cry. Meanwhile, the patient keeps staring with that blank look, his face without an ounce of discernable emotion. He's been reduced to what appears to be an empty shell of a person, but according to his parents he occasionally does show emotion; sometimes he'll sob uncontrollably.

My preceptor had prescribed him Nuedexta for pseudobulbar affect to try to reduce the crying spells. Pseudobulbar affect describes sudden emotional outbursts that are mood incongruent or inappropriately triggered by random stimuli. Does he really have pseudobulbar affect? Or are these episodes just outpourings of frustration and despair? I know his parents wonder the same thing. In any case, Nuedexta didn't seem to reduce their intensity or frequency. Is this the part where I use a PEARLS statement to demonstrate empathy and support? Do I say: "I can see this must be very difficult having your only son reduced to the functional equivalent of a toddler whose only emotional output is an occasional soul-crushing cry. How does this make you feel?"

I feel completely inadequate. I can't even say my generic reassurance, "We're gonna do everything we can to take care of this for you." It just feels foolish. Should I fake positivity? It'd probably be unfair to get their hopes up, and anyways, I've never been much of a faker. At the same time, it'd be cruel to stifle any small sense of hope they might have, so I can't let them see what I'm really feeling: despair. What's left is a sort of indifference, which seems rather cold and leaves me feeling guilty. I usually have no difficulty expressing concern and empathy, but this is too much.

His parents spend a lot of time researching his condition, looking for potential treatments. Glucocorticoids, intravenous immunoglobulin, and plasmapheresis have yielded no improvement, but they haven't given up hope, at least not completely. For over a year they've been trying to get the drug



rituximab, but it's really expensive and insurance won't cover it due to lack of evidence. They hand me a couple of printed research articles on another drug, mycophenolate, telling me that some patients have had great results. I can hear the desperation in their voices. My preceptor says it's relatively cheap, worth a shot.

Bidding them goodbye, I can't help but get an uneasy feeling as I watch the patient shuffle along, blank stare, mouth agape. This could've happened to any of us. No genetic counseling, vaccine, or risk-factor reduction could have prevented this. At least with most cancers there are preventative measures, established treatment protocols, some degree of certainty about prognosis. It's human nature to look for purpose. Why did some little immunologic error destroy this person, leaving behind only a remnant of his past-self to torture his parents?

Some say that everything happens for a reason. I think that's a defense mechanism to protect us from the harsh reality. Not all pain and suffering contributes to some greater good. Some of it is just the product of pure blind chance, little accidents in the great complex machinery. Nature didn't care about this patient. But his parents do. I do. Maybe that's the silver lining to it all. The world may be indifferent to our suffering, but we still have our love for one another. And from this love grows motivation, inspiration to do well by each other. I suppose that's why I got into medicine. To find the victims of this world and rescue them. To prevent tragedies like this from happening in the future. To not just sit down and accept all the horrible maladies that plague our fellow man, but to stand up and fight disease as it rears its ugly head. Not everyone can be saved, but to prevent one family from being torn apart by illness, that is divine.

