



Can you share any examples of patients whose catatonia diagnoses kept them from entering hospice care?

Dr. McCall:

We had the experience of seeing a couple of patients who were thought to be non-recoverable. The easy one was a gentleman who was later in life. He had a dystonia — just odd posture in his hands for many years, had nothing to do with psychiatric illness. And this was sort of a red herring that threw the picture off track, but then he became mute and then stiff in all of his extremities and wouldn't talk or eat. Then the assumption was, "This guy has a Lewy body dementia." Besides having the loss of mental faculties, it can include a certain degree of stiffness. But the picture had to come on so quickly. We thought it could be catatonia and he was treated with ECT and recovered. So we averted a disastrous referral to hospice.

The other case that was so tragic in its beginnings and then euphoric in its outcome — I was on call one weekend at our teaching hospital, and I just happened to be consulted to a patient's room of a young man who was probably 18 or 19. His parents were there, and you could tell they were clearly loving parents and wanted nothing but the best for their son. That was never a question. But they wanted to talk about referring him to hospice, and the reason being is that this fella, I think, was relatively normal until maybe early teen years. And then he became somewhat odd. This progressed over a number of years to the point that by the time he was a late teenager, he wouldn't eat and had lost a lot of weight, and they had to put a peg tube in his side to feed him through his side. He was so obstinate, negativistic and oppositional, he would pull it out — they had to put it back in over and over again, which had to be misery for everybody involved. Then he wouldn't wear any clothes, and he ended up sleeping on some towels or laying most of his life on some towels behind a sofa in his family's living room and was incontinent. His mother had to keep cleaning him up and just everything about it became stranger, and clearly, this was no way for him to live.

When he kept pulling the feeding tube out of his side, his parents thought, "We just can't bear to see our son go through this experience over and over again. And perhaps if God's going to take him, we should just let him go."

He'd actually had an earlier brief course of ECT with maybe 4 or 5 treatments, which didn't do much. So my proposition was different: "Let's not send them to hospice yet. Why don't we do a full course of ECT?" The reason the earlier course was aborted so soon was he didn't like it, which, I would never ask someone to like ECT. Obviously, it's like any surgical procedure — who likes going through surgery? We're not asking you to like it, but some things are necessary.

So I told the family, I said, "You're the parents, you're the guardians because he clearly is not able to make any decision-making on his own. Let's do a full course of ECT, and that could be 10, 12 treatments or more. So we proceeded with that.

The good news is after a lengthy course — and sometimes lengthy courses are required — he got to the point where he would eat and the feeding tube could be removed and he would wear clothes and would sit at the dining room table with the family. And then most dramatically, he was able to go on family vacations to visit national parks. Now, is he completely normal? The usual layperson's sense of normal? No, there's still residual oddities about this young man, and I'm not expecting all of them to be completely reversed. But the fact that we went from considering hospice to visiting national parks is such a dramatic turnaround that you just have to wonder before someone has been considered for hospice — could this be catatonic?