

3-22-19 Negotiating nursing home care

Miss F, Mr. W and I have been through the wringer learning the ins and outs of insurance categories and the rules governing what is and isn't covered, along with being supportive of a ninety-year-old man near the end of his life.

Miss F and Mr. W have been my good, loving friends for sixteen years now. Never a dull moment with these two witty intellectuals! For each other, they are long-term soul mates. Yes, they have feisty arguments, but they always return to their shared love for each other and their mutual loves of poetry, art, jazz and justice!

They asked me to attend a meeting at the nursing home. I wasn't sure what to expect. I wasn't even sure of the purpose of the meeting. Well, I knew that my Miss F, who requested it, was upset and angry and disappointed. She had been told he could have a private room and that is where he began. After two falls, though, he was moved to a shared room. They said the move was necessary and would help prevent falls, as this room was closer to the nurse's station. So, my friend was disappointed that the promise of a private room was not kept.

Emotions are all over the place as it is when you know your best friend and long-term companion, your soulmate is going to die. She advocates for him with passion because she loves him. He needs that, as his tendency is to get sad and quiet and want a nap.

We entered the conference room and people began to arrive and sit in the big chairs. There were at least seven there. Maybe eight. Director, nurse, hospice, social worker and others, whose titles I can't recall formed a large team around the table. My friends were to my right at the end and I, it just so happened, sat in between my friends and the TEAM. That seating arrangement embodied my role. I was in the middle, but I did not know that going into the meeting.

It could have been intimidating.

It was intimidating.

The director of social work, a man who was the closest person at the big table, on my friend's side, began to summarize the situation. He either forgot or did

not know he was speaking to a hearing-impaired person with only one hearing aid and that was on the opposite side of the social worker. After this was brought to his attention, he leaned forward and spoke in a louder voice. A louder blah, blah, blah.

We were not off to a great start.

Other blah, blah, blahs went around the table.

The staff reiterated the reasons why W had to be moved to a shared room. They took turns explaining, with repetition, that being near the nurse's station meant more eyes on the patient. (This was acted out with the fingers from their eyes to my friends, as though these two published authors did not understand the English language.) Some told stories of how being simply nearer to the room, they had been able to intervene and help a person. (Not sure of how; details not given.)

At the conclusion of these reasonings and explanations, a big wig concluded with this: "And so, he has had no falls since being moved to the shared room and this is why, because he is closer to the nurse's station."

Suddenly, I felt alert. They had made an error here in the explanation, yet made it sound like fact. I said, "Wait a minute. That is not scientific. You just described correlation; not causation. You have not stated any data or even anecdotal evidence such as, "While we were walking by, we saw W beginning to lose his balance and ran in to prevent that next fall." So far, this might be only coincidence. He has been sad since being moved to a shared room. Maybe he is staying in bed more often and maybe that is why he has not fallen. Let's talk about what we can do to prevent falls and improve his quality of life here and then re-visit the idea of a private room."

They went silent. No one refuted my claim of correlation vs. causation.

We then talked about adding a raised seat with handles to the toilet seat. (He did not have one and it had not been offered.) Was my friend willing to have assistance in the bathroom? Oh, yes, he was willing, as he had lost his sense of modesty, he explained. (So much is lost before a person is lost.)

Toilet improvements and bathroom assistance. Check!

Miss W pointed out with great passion that the TEAM kept talking about the physical aspects, such as preventing falls, and that this man was a mind and a spirit also. Well, they couldn't argue with that! So, they agreed. She also explained W's need for privacy, which he had none-to-little-of in a shared room. The TEAM

explained there are several areas they could use for quiet reading or music or quiet visits. (They were unaware of these possibilities up until then.)

Privacy issues addressed, as well as could be. Check!

Safe exercise options discussed and agreed upon by patient. Check!

Hospice spoke up, explaining that she had decided he was eligible after all, even though he was receiving a medication that is considered chemotherapy.

Hospice! (They do so much and help in so many ways. God bless them!)
Hallelujah! Check!

We had a plan in place, with the promise that he was top on the list for one of the two private rooms near the nurse's station, should one become available. (Oh, this is at times such a macabre business.) While hoping for a long time and not getting what you hoped for becomes discouraging, I suggested to my friends and the TEAM, that we had a plan of improvements in place, with the HOPE of a private room and that we should accept this plan and re-evaluate in two or three weeks. They said three and we accepted.

Who knew that nursing home care involved such intense negotiating?

I do now.

Cathleen Drinan is the health agent for Halifax, MA. She can be reached at 781 293 6768 or cathleen.drinan@halifax-ma.org