Relentless?

Bob with 1 o has become more and more sleepy and fatigued. He can fall asleep anywhere and anytime. In the car is the most common but he also falls asleep at our dinner table, at restaurants, at doctors’ appointments and of course, in his recliner at home.

Sometimes Bob sleeps for a few seconds and sometimes the little nod-off becomes a nap. Sometimes he’s talking and mid-sentence his eyes go shut and he’s out like a light.

Our primary care doctor has counseled me that Bob’s dementia is progressing and along with that comes more and more sleep. The disease of Alzheimer’s/Dementia is much more than a memory disease. It is a disease of the brain. And since the brain is the control panel for all your body, every function of one’s body is affected. Bob has many dementia related issues, and one is just being tired.

So you think I would just accept that and take it for what it is. But no, I feel compelled to pursue other avenues and take myself down another path, dragging Bob along with me. I started to realize that it is highly possible for Bob to have sleep apnea. He doesn’t snore but he does sleep and wake all night long. Sometimes he wakes with a gurgle sound and sometimes he coughs. He is not aware of this and I’m really not sure if it goes on all night. All I know is that he can’t keep himself awake in the daytime no matter how long he is in bed “sleeping” at night.

In trying to get Bob tested for sleep apnea, I had to push his primary care doctor a bit. He finally made the referral and told me it was because I was “relentless”. I took that as a compliment! Yes, I wanted to make sure that there was not anything we were overlooking that could be done to help Bob. He may live a long time, or his days may be numbered—all I know is that I want Bob to have the best quality of life he can. Even with dementia.

The physician’s assistant at the Sleep Clinic was so helpful and caring. She saw that I needed to have Bob be checked so that I could either move on or move ahead depending upon the diagnosis. She also warned me that dementia patients do not take well to wearing the CPAP Masks that are used for sleep apnea patents. She said that even if it were determined that he has sleep apnea, there is no guarantee that much could be done to resolve it. Sleep apnea patents must want the benefits of the better sleep and that makes them willing to wear a possibly uncomfortable mask. Most patients can understand that cause and effect and understand the benefits of wearing the mask. Not someone with severe dementia. To them its just another thing their caregiver is forcing them to do!

The testing for sleep apnea is much easier than I anticipated. I made Bob’s appointment and we attended a class on how to wear the monitoring device and do the testing at home. Seemed simple enough. I thought we were on our way to better sleep for Bob!

Explaining the class and the monitoring device to Bob was the silliest conversations ever. Imagine explaining it to young child. Just a lot of disinterest and blank stares. At bedtime, when I went to help him put on the monitor and finger probe, he protested. I went through the explanation a few more times, always referencing his primary care doctor by name and telling Bob that his doctor was hoping to solve his sleeping problem and needed this overnight test. I know he doesn’t care if I’m upset with him, but he wouldn’t want to make Dr. Nafes upset! So, he crawled into bed wearing the monitor on his left wrist and with the finger probe firmly attached. Whew…. all was good.

2 ½ hours later, I was reviewing the paperwork on the

equipment and I realized that I had never pushed the START button. Oh my, Bob had been asleep for 21/2 hours with out the monitor doing its job. I was able to push the start button without waking him. Whew… disaster averted.

So we both slept. I thought. At 5 am I woke up when I noticed Bob was getting out of bed. I told him it was ok now to take off the monitor and I would help him. I reached for his hand. Didn’t find it the monitor. Checked the other hand. Just in case. Didn’t find it. Yes, the monitor was not on either wrist. It was sitting on the nightstand. Bob had no idea as to when he put it there, but he did admit that he took it off. He said he was fine and didn’t need to wear it.

I felt so defeated. The equipment is only for a one-time use. Any chance of it collecting the required data was slim. I couldn’t be mad at Bob. I was warned that he would have difficulty with the testing equipment—even though I thought it was so simple to do. I just packaged up the equipment and drove to Kaiser Zion to drop it in the drop box. Maybe they will be able to get an adequate reading from the short amount of time that he had it on his wrist. Maybe. Bob slept most of the way there and all the way back home.

So it took all of that long story to get to the important part. At least this is the important part for me.

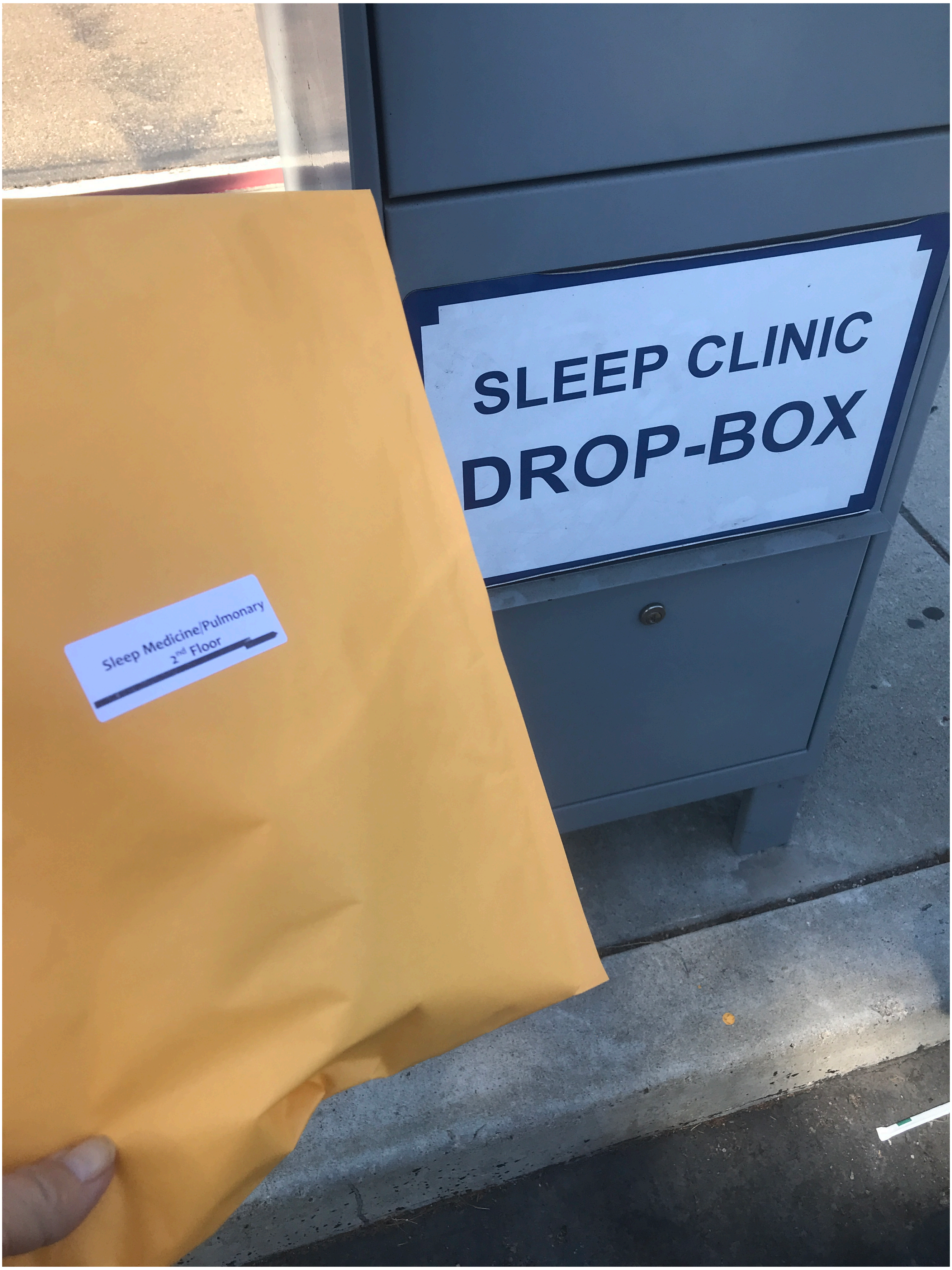
Was I pushing and trying to get this sleep apnea test for Bob’s best interests or mine? Am I expecting him to improve or change? Am I not accepting that he has a rapidly progressing disease that brings so many health issues? Am I still clinging to chances that something can be done to improve his mental and physical health? Do I have unreasonable expectations of his behavior? Am I making things difficult for him to try to make things better for me? Am I considering what is best for Bob? What are my motives?

Being entrusted with the care of another is scary. How do I know I’m making the right decisions?

So, as I await the results of the sleep apnea test, this is my prayer:

Dear Heavenly Father, I need wisdom. I have questions and situations to sort out. Please fill my heart with Your wisdom and not my foolish desires. Guide me on the path I should take. Please make me a loving caregiver and not a relentless caregiver.*

*Relentless: Someone who is relentless is determined to do something and refuses to give up, even if what they are doing is unpleasant or cruel.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