

## Aging Happens: Communicate with your doctors about dementia

By Ellen Waldman April 26, 2015

I still have relatives who live back east. My 86-year-old uncle has been having serious memory issues for some years now. I spoke to his wife, my aunt, and asked her if anyone has diagnosed him yet. This was after she told me he's taking a well-known dementia medication. She said, "What's to diagnose? It's old age."

You should know this is not a natural part of old age; it's a disease. But sometimes, a doctor does not actually give their patient and their family the diagnosis. I also know how helpful and important it is to have this correctly noted, so preparations and education can begin.

I once sat in the exam room with a person who had moderate dementia. He could no longer self-report on his health or other problems. The doctor asked him if he was sleeping well, and he said he was. I respectfully said to my client, his patient, that I had heard that he was up quite a bit at night and perhaps he was not sleeping that well. The doctor's reply was, "Well, I have one yes and one no."

Hopefully, doctors understand that the information given to them by the patient may in fact be less than accurate. We sure don't want to contradict or argue with the person who has cognitive impairment. Providing an accurate report without embarrassing or contradicting the person with dementia in front of their doctor is key. There is now a better way to be able to do this.

Most local doctor's offices and medical centers are now set up with patient portals. This is the online system you may be familiar with called the Epic system. The purpose is to have all medical information in the electronic medical record or EMR. Providence has their version of this called mychart/providence.org and Asante has one called asante.org/MyChart. Next time you're at your doctor's office, sign up for this.

You can read your reports, get lab results, schedule appointments and, most importantly for this topic, send information about the person with dementia to the provider. When you arrive, they will have read your questions, concerns and the current status report. This way, the family or caregiver can provide the needed information behind the scenes.

Before the use of these patient portals, I would fax a letter to the medical assistant or nurse to report on the client's status. I would ask that the doctor read it before coming into the exam room. If your physician is still not hooked up with the online MyChart access, or another patient portal, this is the best route to take. It makes a big difference to have an accurate account ahead of time.

On the Alzheimer's website, you will find articles about communicating with your physician. One is called "Working with the Doctor" (www.alz.org/care/dementia-doctor-patient-communication.asp). There is also a brochure called the "Principles for a Dignified Diagnosis" that offers these guidelines for physicians. You might assume that all providers are conscious of and comfortable with these recommendations, but it may not be the case. Here are a few suggestion from the brochure. You can find the rest online:

- 1. Talk to me directly, the person with dementia. (I will add that if they are more advanced in the disease, they may not be able to fully understand. Still, no one wants to be ignored.)
- 2. Tell the truth. (Although it's not as common, one physician would not tell their patient they had dementia. He felt he didn't want them to lose hope. It's recommended that people be told and allow for hope to come in another form, such as good quality of life care.)
- 3. Give me tools for living with this disease. (A good idea, but I would not expect doctors to know all the local resources. For that info, call the Medford Alzheimer's office, 541-772-2230, or check the website online.)

Communication in all directions is so vital for good medical care. With a dementia diagnosis, there are some ways that are more effective than others. Educate yourself first, and then ask your physician to participate in this dialogue with you. It's allows for a much better outcome for everyone.