

Notes from Primary Care

It is common for older people to have a long list of diagnoses on their medical records. Some of these might surprise them if they were to look. Surprise happens too often when one of those diagnoses is dementia, and today was no exception.

Mr. Thomas, an 83-year-old man, came to New York City from the Dominican Republic as a young man. His regular doctor had recently retired, and I would be his doctor now. Today Mr. Thomas arrived early for his appointment and came alone. On his problem list was a diagnosis of “vascular dementia.” I wondered, “Does he know about this diagnosis? Will he be angry if I bring it up? Can I even tell if it's accurate? How should I proceed?” While I realized that these were my fears, I wasn't sure how or where to start.

So, I started from where we are now. “Nice to meet you! How are you doing?” After a pleasant exchange, I continued: “I see you came by yourself today. Is there anyone who might come along to our visits?” “Nope, just me. No one else to help me. I have a daughter in Maryland. She wants me to move there and live with her.” “What do you think about that?” I asked. “That'd be OK. She wants to talk to you.” I realized, “An opening! Perhaps she can help, and I'll get more complete information. But maybe it will be even more difficult to talk about dementia...”

“Can you talk to her now?” he asked. He called his daughter on his cell phone and put it on speaker for a 3-way conversation. After the usual introductions, I asked them both if they had any concerns. Mr. Thomas had none to share. That he lived alone was his daughter's chief concern - especially because he was forgetting to do essential things sometimes, like take his medications on time. Now I could ask the question I wanted to ask next: what were his, or his daughter's, concerns about his

ability to remember or think clearly? “I do forget things,” he said, “but I’m OK.” His daughter chimed in, “He forgets a lot of things - I’ve started calling him several times a week to keep him on track. That’s a big reason I want him here with me. It will be easier for me. I need to remind him to take his medications and now, I have to be sure he has food in the apartment, I have to make sure that he eats and all the bills get paid – they don’t all get mailed to me directly.” Mr. Thomas smiled. “I’m getting older, I know, that’s what happens I guess.” I offered, “Yes, this happens to lots of people, for different reasons. It can be harder to do the things you need or want to do every day.” Now I was starting to hear about changes that could have been noticed by his previous doctor – perhaps that’s what led to his making a diagnosis of dementia.

“I see in your medical record that there is a diagnosis related to the problems you’re having with memory. Did anyone ever talk to you about your memory, or mention that you might have a condition we call dementia?” Mr. Thomas shook his head no and his daughter asked, “that is in his record? No one ever talked to me about it!” I explained that sometimes a diagnosis turns up in the medical record without any mention to the patient or their family. Sometimes there might be a conversation with the person – but that could be forgotten. (After all, dementia is a disorder that affects memory and thinking. Not involving family? What a ridiculous omission!)

I apologized on behalf of all of us doctors --too many times we make a diagnosis of dementia that is never shared with the affected person or those in a position to help at home. But now we had the opportunity to put that right, to explain what it means to have a diagnosis of dementia and to be encouraging. We would look into everything that could be making Mr. Thomas’ memory worse--and there were several possibilities. His sleep had been poor; that, and the medication he was using for it, could both affect his memory. We could try other ways to help him sleep that would be better for his brain. He also had high blood pressure that needed everyday medication, a healthier diet, and consistent, daily physical activity, but he no longer kept to a schedule and rarely saw or talked to anyone he knew. Moving closer to his daughter in Maryland could provide that missing companionship, stimulation, and

support for a healthy routine. Given the possibility that 'tuning up' his routines and medical treatment could improve or maintain his function, I was optimistic for his future, but cautious too: "It seems like we have a lot to work on that may provide real benefit for you. You are lucky to have such a great daughter who wants to help. With the changes I'm suggesting, your memory might get a little better - but we have to be prepared that it might not, and it could even get worse. We hope we can keep things the same for a long time - but only time will tell." His daughter thanked me profusely. "I wish we could have had this conversation three years ago." Looking back, I was embarrassed by my initial hesitancy to bring up the issue of Mr. Thomas' diagnosis. I should have trusted that my patient and his family would help me get it right.