

# Virtual Mentor

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## CLINICAL CASE

### When Home Care Is Not Enough

Commentary by Mitchell T. Heflin, MD, MHS

“Good morning Mr. and Mrs. Frank,” said Dr. Woods as he greeted his patient’s family. “Glad you could come in with your mother. Her blood pressure is fine and her heart and lungs sound good. Are you noticing much change in her ability to get around or her mental status?”

“Well,” replied Mrs. Frank, “that’s something we wanted to talk to you about today. We now have an aide who comes in five times a week for an hour or so, and she helps bathe and dress my mother-in-law. I’m there most evenings and every night, so I can watch her then. She’s doing okay, I guess. She gets confused more easily now, and when she gets up to walk, I worry about her balance.”

“Don’t get us wrong—mother’s okay, all things considered—we’re doing the best we can.” Mr. Frank continued, “I’m not sure what to do about her wandering off. I sleep during the day since I work nights now, and once last week I found her wandering down the street. A while back, I was awakened by the smell when she put a piece of chicken wrapped in foil in the microwave.”

Dr. Woods looked at his patient and her caregivers. He knew he was about to raise a sensitive subject. “It sounds as though you are well taken care of,” he said to his patient who smiled pleasantly. Then he addressed Mr. and Mrs. Frank. “As we discussed before, your mother’s Parkinson’s is fairly advanced, and she will require more supervision and care as time goes on. What are you planning to do when she needs round-the-clock companionship? Have you given any more thought to finding her a good nursing home?”

Mr. Frank sat straight up. “I know you mean well, Dr. Woods, but where my mother lives is *our* business. When we told you about my mother’s problems, we just wanted to share with you what was going on. We thought maybe you could help us a little. We did the home evaluation like you wanted; home health care has helped a bit, but we can’t afford to have someone there all the time. My wife skips most of her Monday and Thursday bingo nights, and I work nights so that mother’s never in the house alone. She took care of me, and now I’m taking care of her. We’re *never* going to abandon her to some strangers!”

Dr. Woods paused and responded calmly, “As her physician, it’s my job to let you know what her needs will be, probably in the near future. Her care isn’t going to get any easier.”

After the Franks left, Dr. Woods stepped out of the room and consulted a colleague. “This family is obviously doing the best they can for my patient, and, in the earlier stages of her dementia, she did state several times that she never wanted to go to a nursing home. But with each visit, I’m more and more concerned for her safety. I’ve tried to make her family aware of my concerns, but they are sort of stuck. They can’t afford the home care their mother needs and they’re determined not to have her in any kind of skilled nursing facility. I would hate to alert the adult protective services, but I’m wondering if that’s the route I’ll have to take. I don’t think this living arrangement is very safe for my patient.”

### **Commentary**

The dilemma faced by Dr. Woods and the Frank family is familiar to anyone practicing medicine in the modern era. Like the senior Mrs. Frank, many older adults suffer from chronic conditions that, over time, result in progressive loss of the ability to live independently and to provide basic self-care. Heart disease, stroke, COPD (chronic obstructive pulmonary disease), arthritis, dementia, and Parkinson’s disease are all progressive conditions that ultimately threaten function and quality of life. Eighty percent of adults over the age of 65 are afflicted with at least one chronic condition, and 50 percent, by at least two [1]. Concurrent with this decline, caregivers—usually spouses and children—face a number of challenges such as acquiring the skills needed to help their older relatives with daily activities, balancing their personal and professional demands with their caregiving, and, as in the Franks’ case, determining the level of care and attention their loved one needs.

As physicians, we encounter our own set of challenges with these patients and their families, trying to assess the patient’s safety and negotiating the complex and often emotion-laden issues surrounding level of care. In the end, of course, each case is unique, and there are no formulae for solving these problems. A few basic guidelines, however, can help Dr. Woods navigate this difficult course.

*Maintain respect for the patient.* Regardless of her disease process, Mrs. Frank is still the patient here, and it is important for Dr. Woods to demonstrate that in his interactions. In visits with her and her family, he should engage Mrs. Frank first, assess her comfort and concerns, and obtain her “blessing” to discuss her care with her family. For patients with Parkinson’s disease this can be difficult, inasmuch as they often appear disengaged, with masked expressions, hypophonia, and bradyphrenia [2]. Even with patients who suffer from cognitive decline, physicians should still display respect by making them the center of the visit.

*Assess the patient’s capacity to make decisions.* Before accepting a patient’s choices at face value, physicians must have some understanding of their decision-making capacity. This can be difficult to do in a brief encounter, and capacity can change over time with acute illness, medication, mood, and, most importantly, the nature of the decision at hand. Brief cognitive tests, particularly those for executive functions like clock-drawing, verbal fluency, or Trail B Test (a neurocognitive test) can help

the physician appreciate the patient's ability to process information and solve problems. In addition to considering cognitive ability, the nature of the decision being made must be weighed. Mrs. Frank may not have the capacity to manage her finances or a complex medication regimen safely but may still be able to discuss general preferences for end-of-life care [3].

*Offer the family the option to talk more openly away from the patient or via phone.* Families are sometimes uncomfortable sharing their true concerns in the presence of loved ones, but they still need opportunities to express their worries, frustrations, and challenges. Simply inviting the family to wait in a conference room during the exam and then providing them time away from the patient may decrease tension and improve their ability to speak openly. If time does not allow for a separate conversation, then offering a phone appointment may suffice.

*Acknowledge the stress experienced by the family.* In our case scenario, Dr. Woods briefly recognizes the family's efforts to provide Mrs. Frank's care before he begins addressing the level of care he believes his patient needs. The son reacts defensively and emotionally. Indeed, these can be highly charged conversations that demand careful management by the physician.

An alternative way to begin the conversation about the appropriate levels of care is to start by "checking in." Families need time to decompress and often bring pent-up emotions—including anger, frustration, anxiety, and depression—to the visit. Give the family you are meeting with time to tell you how they see the situation and how it's going for them. Caregivers are usually willing to open up about problems and ask for solutions, but this is less likely to happen if they are put on the defensive. Dr. Woods may have had a more successful interaction if he had started the conversation with "So tell me, how things are going for you?" "What concerns do you have about your mother's health?" "What do you see happening in the future?" or "How have you planned for this situation?" The Duke Family Support Program offers language and strategies for conducting these important but difficult conversations [4].

*Talk in terms of specific needs before discussing solutions.* Determining the needed level of care for older adults is complex. Discussions about assisted-living facilities and nursing homes can trigger images of musty, dark institutions or remembered stories from the press about neglect. Physicians sometimes stumble in conversations about level of care because they do not think about the patient's specific needs before declaring what they believe ought to be provided. Rather than treating care as a dichotomous decision (either skilled nursing facility *or* home care), conversations with patients about activities of daily living—bathing, eating, dressing, using the toilet, and ambulation—provide a framework for discussion about needs and safety. Patients and caregivers may be more likely to acknowledge that "I need help with X" before they declare that "I need to move to a nursing home." This type of dialogue also gives physicians insight into the specific challenges a patient and family members are facing and allows him to either build a case for a change in level of care

or to offer a menu of solutions that may allow the patient to remain in his or her current living situation.

*Talk about specific safety concerns.* Dr. Woods' major concern, of course, is his patient's personal safety. Given the unfortunately high prevalence of elder abuse and neglect, and the patient's risk of personal injury from a fall or an accident, this is a valid concern [5]. Again, inquiring about the patient's and family's current living situation is important. Ask the patient—without the family present—about feelings of neglect or abuse and look for signs and symptoms like unexplained weight loss, contusions, pressure sores, or poor hygiene that might indicate an unsafe home environment. Ask the family about safety and monitoring in the daily routine, including medication management, use of heat-generating appliances, driving, and availability of firearms. Detailed information provided by nurses and social workers who make home visits, such as the one requested by Dr. Woods, can be useful in this circumstance. If there are concerns about the patient's wandering, then recognizing the triggers (such as anxiety, boredom, loneliness, restlessness, pain, and discomfort) and providing an environment with reliable monitoring and outlets (e.g., exercise or activity) may suffice. Patients may also be enrolled in the Safe Return Program through the Alzheimer's Association. If concern for abuse or neglect remains, then an assessment by a licensed social worker or a call to Adult Protective Services may be in order.

*Refer to community-based resources including social work and health agencies.* Perhaps most importantly, Dr. Woods should recognize the limits of his own knowledge and training and should recruit other health care professionals to assist him. Social workers, particularly those experienced in the care of older adults, are trained to assess self-care capacity, caregiver strain, and personal safety. They are knowledgeable about professional and community resources for respite care, long-term care, and caregiver support. Social workers can also assist in the financial aspects of home care and, if agreed upon, skilled nursing facilities, by assisting the family in navigating the complex process of assessing Mrs. Frank's financial status and submitting applications for assistance programs, including Medicaid. While few—if any—of these problems are ever easily solved, most communities have low- or no-cost options for companionship or day care, which may provide the Franks with key respite time.

*Provide anticipatory guidance and encourage advance care planning.* With any chronic condition, but particularly with neurodegenerative conditions such as Parkinson's disease and dementia, advance care planning is essential. From the physician's perspective, this involves discussions about prognosis and treatment preferences early in the disease process. This affords patients and families the opportunity not only to discuss their preferences but to gain a better understanding of what to expect and how to prepare. These discussions often take place when a patient is writing a living will and designating a health care power of attorney. For physicians like Dr. Woods, such discussions may help to avoid a confrontation like the one he encountered with the Franks. Early referral to caregiver resources and

support groups may help patients and their families deal with the stress, strain, and grief these diseases present.

### References

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### Relevant Web Sites

Duke Family Support Program, <http://www.geri.duke.edu/service/dfsp/index.htm>.

National Alliance for Caregiving, <http://www.caregiving.org/>.

National Family Caregiver Association, <http://www.thefamilycaregiver.org>.

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