Dear Dr. Jeff:
Our director of nursing frequently asks me to participate in family meetings with anxious or unhappy families of new residents. This isn’t in my job description and leaves me feeling uncomfortable at best. Sometimes I would rather have a root canal than face another angry daughter. I’m not sure what is expected from me, particularly as I am not the attending physician. I don’t want to refuse to be “part of the team.” What do you suggest?

Dr. Jeff responds: Physicians often wonder what is expected from them during family meetings, especially since these commonly occur shortly after admission and relate to transition issues. Since it is well within the capabilities of the nursing staff to inform the family about the resident-assessment process, the care plan, and all the information that will be gathered for the Minimum Data Set, the need for physician involvement seems unclear.

Finance and social services can explain benefits as well as help with adjustment issues. Moreover, these meetings frequently occur before the results of the workup are available, leaving unanswerable all-important questions of diagnosis or staging of known diseases and prognosis. When the physician attending the family meeting is the medical director rather than the attending physician, she or he may have barely seen the patient and be unfamiliar with many medical details. When the family has complaints, they are usually related to issues like call-bell response, over which the medical director has virtually no control.

So why, oh why, does the medical director “need” to be there?

First, you are there to listen. Multiple studies have shown that family satisfaction with meetings is directly correlated with the amount of time that they speak. The family is eager for you to see their loved one as a special person. They may believe, rightly, that critical information about the patient has not been transmitted from the acute care system. The family is often the repository of vital information about the patient’s past medical history and circumstances. In some cases, they are a virtual portable medical record with copies of test results, names and contact information for previous consultants, and valuable information regarding the new resident’s personality.

As you listen, you have the opportunity to ask significant questions. For example, if the transfer summary includes a diagnosis of colon cancer, you want to know when this was diagnosed, what treatment was given, who the surgeon and oncologist were, and if chemotherapy was discussed and either given or refused. Families are also generally willing to accept assignments of their own at such meetings, such as going to a relative’s house to bring in previous medications or track down the business card of a treating physician. Making the family part of the treatment team is a far, far better strategy for the facility and the resident than demonizing them as the enemy. As I said in a recent column, families should be part of the care team.

As the medical director, you are unlikely to know the medical details of every resident, but you might consider bringing along the patient’s chart so some information can be confirmed or corrected. Wrong information leads to wrong conclusions and to distrust. If the results of significant tests are available, you can interpret them for the family. If important information is missing, everyone should come out of the meeting with a plan to obtain that information.

The medical director’s statutory responsibility to “coordinate care” may mean that tracking down this information or ensuring that necessary tests are done is partially your responsibility. Also, as the public face of medicine in the facility, you need to be sure that the information transmitted to the family is accurate and balanced. When the meeting has been called by the facility, particularly for a patient who is doing badly, you need to be the knowledgeable source regarding the risks and benefits of hospitalization or end-of-life options.

Even when hospitals believe that they have provided information, the medical significance of diagnoses or treatments may not be clear to patients and families. This, in turn, can leave them confused about our care plans. Some families may not connect Dad’s insulin shots in the hospital or his getting fruit instead of cake for dessert with a diagnosis of diabetes. Families may have been told that the patient had aspiration pneumonia but may not understand the word aspiration or how that might call for a neurologic evaluation, speech therapy services, or a modified diet.

Teacher, Teacher

This leads to the second important role of the medical director at the family conference, and that is as medical educator. While lecturing is rarely a good idea, a short summary of the known medical information and how that informs and directs the care plan can be invaluable. Increasingly, patients transferred from hospitals have been under the care of hospitalists or surgeons without prior knowledge of the patient. Now they are being transferred to a nursing home (perhaps unhappily) and are again assigned to a professional care team whom they have not chosen and have never met. If placed in a similar circumstance, you would probably be anxious, too.

Even when information transfer has been handled well, families benefit from a review of what came from the hospital. This may reinforce their understanding, or it may be the first time they have received significant diagnoses or test results. They need to come away feeling that a well-trained and knowledgeable physician is overseeing the care of their relative.

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As the medical director, you represent the quality of physician care available at your institution. This is particularly crucial given the negativity that many Americans attach to the phrase “nursing home.” Frightened by headlines, exposed to opportunistic legal advertising, and aware of some undeniably unscrupulous operators, families approach nursing home placement, be it short term or long term, with considerable trepidation.

Families of nursing home residents are often anxious and confused. Sometimes they are also hostile and angry – at times with the facility but often with each other, themselves, or even the resident. Placement of a loved one in an institutional setting arouses feelings of loss and guilt, particularly as society reinforces the message that families are supposed to care for their own at home, while finances and medical necessity often make that impossible.

Of course, there are a small number of families who are genuinely difficult. Dr. David A. Smith, CMD, a former AMDA president, and Dr. Rebecca D. Ellon, CMD, at Johns Hopkins University, Baltimore, have pioneered the concept of “conflicted surrogate syndrome” to describe these individuals. The hallmarks of this syndrome are behaviors that significantly exceed the normal concerns and complaints that we expect from anxious family members, particularly during the admission process. But we can’t tell the truly dysfunctional from the merely troubled until we give the family a chance.

Principal, Principal

Along with your roles as listener and educator, your third major function is as a validator. For the general public, you represent status, prestige, knowledge, and power. As the “senior doctor” in the facility, you are a very important person. Families are used to the hospital hierarchy. Your presence at the meeting underscores the importance of the meeting and the value that the facility places on this process. It confirms the accuracy of the information provided by the other team members in their individual assessments.

Although the nursing staff may know the resident much better than you, your nod affirms their information. We may not approve of these undemocratic (and frequently sexist) notions, but it is foolish not to recognize the social dynamic and take advantage of it.

The family conference offers, then, a golden opportunity to present the nursing home for what is really is – a specialty institution. Thus, much as we may criticize hospitals both for their seemingly tone-deaf approach to the needs of the frail elderly and to the legitimate concerns of their families, the truth is that they often don’t know any better. We do.

We have the luxury of sufficient time to evaluate the whole person. When the social worker on the team complains that hospitals “dump” difficult patients into nursing homes, I reply that the hospitals are, in fact, referring these patients to experts.

At the family meeting, we have the opportunity to address the concerns of distressed families, provide accurate and nuanced explanations of their loved one’s diagnoses and overall prognosis, and share with the family the difficult task of creating a care plan that both addresses the needs of the patient and responds to the patient’s strengths and individuality. The opportunity to provide this information to residents and their families is actually one of the pleasures of practicing in long-term care.

The stresses that accompany this process are a measure of its difficulty.

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