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That "Difficult" Mr. Thurston: What's the Home Health Agency to Do?

Ronald and Andrea Thurston have been married for fifty years. They live comfortably in the retirement village they moved to six years ago, after Mr. Thurston retired from his job as a unionized construction worker. Andrea had stayed at home caring for their home and their two children who now call but do not visit often.

Mrs. Thurston recently suffered a major stroke that left her right side paralyzed. After the stroke she spent two months in a rehab unit and then another two months in a nursing home to continue her therapy. While in the nursing home she developed a stage four pressure sore. She was discharged home to continue her therapy. Grove Hill Home Health Services provided needed nursing services, and Mr. Thurston was trained to provide wound care. He seemed ready and eager to do the job.

After her second visit the home health nurse observed some behaviors that troubled her. Most importantly Mr. Thurston was not following the doctor's instructions, so the wound was not improving. His care seemed overly eager, perhaps even aggressive; for example, he cleaned the wound as often as four times a day. Further, his dominant, take-charge attitude gave his wife few opportunities to speak. Yet he seemed quite devoted to her, insisting that he would

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continue caring for her as he had for the past fifty years.

The nurse tried, once again, to teach him proper wound care, but when she returned he had again done it "his way." She explained why wound management had to be done a certain way. He responded by calling her supervisor to complain. Both supervisor and nurse came to the next visit and explained that they could not continue to provide care if he did not follow instructions.

Unfortunately, vigorous, even aggressive, wound care seemed to be Mr. Thurston's style. The wound became worse. Mrs. Thurston's doctor asked a wound care specialist to see her, but Mr. Thurston's behavior did not change. At a family-team everyone urged Mr. Thurston to follow the instructions for proper wound care. He did better for two weeks, but the nurse feared he would go back to his older ways just as the wound began to improve.

What can Grove Hill Home Health services do about Mr.

Thurston's insistence, despite explicit and repeated instructions, to do wound care in his own way? Isn't this situation a clear example of the noncompliant caregiver?

Perhaps the most critical task we face when confronting a difficult ethical situation is to define the problem. This definition informs the values we choose to protect and the actions we recommend. Yet, rarely is there a single way to frame an ethical problem. Our professional roles and our ethical orientation influence how we see a situation. In this case, we might ask: Is there an alternative way, other than noncompliance, to define this problem? Could we, for example, define the problem not from a professional perspective but from Mr. Thurston's point of view? He might frame it as a problem of professional interference with his commitment to care for his wife—a responsibility he feels he has assumed for fifty years. Or the professionals might redefine the problem more broadly: Mrs. Thurston is not getting the care that she needs. What would it take from all parties to assure that she receives efficacious wound care while preserving important relationships?

If we redefine the problem from Mr. Thurston's perspective or that of the broader practice aim—caring well for Mrs. Thurston—the values we seek to preserve focus on relationships and the meaning

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of care from ethical as well as clinical perspectives. These values might lead us to develop a partnership in care, supporting Mr. Thurston’s commitment to care for his wife, and respecting him by acknowledging his needs at this difficult time while helping him to modify his definition of what loving—and appropriate—care entails. To this end, the team might ask: Did anything happen in the very beginning of Grove Hill’s intervention that contributed to this adversarial relationship? Are they showing respect for this marriage? Are they dismissing Mr. Thurston’s belief in his own competence and knowledge of what is “good” for his wife by their way of instructing him? Are they delegating tasks to him or bringing him actively into care planning? What changes might they make in their approach to him? They might also examine how to build upon the long-established pattern of relating between the couple. How did they make decisions in the past? How did Mrs. Thurston express her wishes prior to the stroke? Had Mr. Thurston always sought to do more rather than less, and had anyone succeeded in changing that pattern? What are his motivations in caring in this particular way for his wife?

Is Mr. Thurston’s behavior a control measure or his way to advocate for his wife by giving her “better” care than the “cheap” healthcare system offered? Does it reflect his fear

that she might die, or his anger that his life is so dramatically altered? Appreciating and responding to the meaning of his behavior is one step toward helping him to change it.

Are there other ways of meeting his needs and responding to his fears? Taking as guides Mr. Thurston’s experience as a construction worker and his belief that he knows his wife’s needs, they might, for example, reenvision how they teach wound care. Analogies to his work, diagrams, and participatory discussion of aims are possible. While he may be hotheaded, controlling, and angry, he might also have convinced himself that more is better—better for the wound and better for his self-image as a devoted spouse. Being close to the situation the team will be able to identify action not visible at this distance.

It is clear that the care team’s concerns are legitimate and Mr. Thurston’s actions problematic, but it is also possible that the team has inadvertently undermined his agency in his wife’s care. The goal of this discussion is to encourage team members to retell the Thurstons’ story from another perspective. By so doing, team members can identify alternative ways to define the problem, recognize the different values that each person in the situation might hold, and open paths of action that might have otherwise been obscure or even invisible.

e-Ethics provides discussion of important ethical issues in clinical care and organizational life. In specific cases, fuller ethical analysis may be required. The discussions in e-Ethics should not be construed as legal advice and do not necessarily represent official positions of Advocate Health Care.

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