

The Case
of the Careless
Caregiver

*Case and questions
compiled by
Rosemary Flanigan
and Robert L. Potter*

Grace H. has spent all her life teaching high school English in Pine Junction. She retired ten years ago when she began to suspect that she was suffering the early stages of dementia. Shortly after she retired, Grace, who has never married, sold her home and moved into Happy Valley Nursing Home where she has slipped into what the doctor agrees is Alzheimer's disease.

Grace has lived at Happy Valley for nine years and appears to be content. Before the dementia progressed, she could be found wherever a group had gathered and her laughter could be heard above the others. But the progress of the disease has been relentless and Grace has become more withdrawn. She has been spending more time in her room, communicating with fewer and fewer words.

Last month, the staff began to notice a marked change in her. Before, she would be found sitting in her chair when she was in her room; now, aides find her back in bed, complaining of being "tired." She is eating less, often is reluctant even to go to the dining room, and appears paler than usual.

The Director of Nursing at Happy Valley has consulted with her staff and they decided that Grace should be taken to Pine Junction Community Hospital to see what is causing her listlessness. Tests at the hospital show that her platelet count is abnormally low, but they admit they do not have the technology to discover why it is so low. Her attending physician calls the director of nursing at Happy Valley to say that he recommends sending Grace in an ambulance 35 miles away to City Hospital. The head nurse talks with the administrator of the facility and the latter contacts Grace's

brother, her only living peer whom Grace has named as her durable power of attorney for healthcare decisions. He says, "Well, we have to find out what's wrong with her, don't we?" and consents to Grace's being transferred.

She has been in City Hospital for six days now, having had numerous blood drawings, a CAT scan, and a bone marrow test. It is clear that the abnormal functioning of her spleen is causing the problem. She is receiving an experimental drug which, though it will not directly influence the condition of the spleen, does allow it to produce some platelets, and she is receiving supplemental nutrition through an indwelling IV, but this has resulted in swelling in her arm making it twice its normal size and it is painful. Her brother comes to visit and asks the nurses, "Why are they doing all this?"

Preliminary questions to consider

Did Grace have an advance directive?

Of course, and it stipulated that she wanted nothing extraordinary to be done in the event that she was dying. But the administrator and chief nurse did not think about Grace's advance directive. When they called her brother to get permission to take her to Community Hospital, they did not think she was "dying"; her body simply wasn't making enough platelets.

Did she have a Do Not Resuscitate request?

Yes, and it was also in her chart; but is anyone thinking about resuscitation? The professionals are concentrating on her spleen.

Is Grace's brother contradicting himself?

Wasn't he the one who consented to her "voyage to discovery"? Can one justify interrupting the "voyage"? How explain his asking, "Why are they doing this?"

Has "caregiving" gone wrong here?

Discussion

Questions for discussion:

1. Ought the judgment, "Grace is not dying," determine the course of treatment she receives?
2. What ideas are implied in her brother's question: "We have to find out what's wrong with her, don't we?"
3. At what point in Grace's journey would you argue that "caring" for Grace would suggest a different turn of events?
4. Grace's brother makes two statements in our story. One implies that gaining knowledge is a sign of "caring." What does the second statement imply?
5. What does this case tell us about interpreting an advance directive?