
The Forgetful Mourner

Mrs. C., an eighty-six-year-old Italian American woman, is moderately demented due to Alzheimer disease. She had been living with her son Tony and his wife Isabella, but when Tony suffered a heart attack two years ago, everyone agreed that it would be better if Mrs. C. were moved to a nursing home. She adjusted to life at Beech Hill quite successfully, and enjoyed the weekly visits from her son and daughter-in-law.

The director of the Alzheimer Unit at Beech Hill, Dr. L., somehow reminded Mrs. C. of her son. She developed a pattern of asking Dr. L. four or five times a day how Tony was doing. Dr. L. always told her, "Tony isn't in good health, but Isabella is taking good care of him." This answer seemed to satisfy Mrs. C., who prayed for Tony and Isabella because, as she said, she wanted to do everything she could for them.

Last month, word reached the nursing home that Tony had had a massive heart attack and died. Dr. L. consulted with the rest of the staff and decided Mrs. C. must be told—a task he undertook himself. She understood what he was saying and begged to attend her son's wake, so arrangements were made for a member of the family to take her there, and an aide helped her into her good black dress.

In the days immediately following the funeral, however, Mrs. C. forgot her son had died. She began asking Dr. L. the old question, "How's Tony doing?" After another consultation with the rest of the Beech Hill staff, Dr. L. decided that he should try, at least for a while, to answer her question truthfully.

Each time he did so, Mrs. C. experienced the pain of her loss as if for the first time—she became distraught and could not be comforted. This was hard on everyone, but Dr. L. hoped persistence and patience would eventually help her to retain the bad news. The only alternative, it appeared, would be a sustained deception on the part of the staff as to Tony's whereabouts.

After Dr. L. had told her of Tony's death perhaps fifteen times, the aide wondered if the black dress Mrs. C. had worn at the wake might prod her memory. The dress was brought out and put on her, and it did help her to remember about her son. She no longer asks how he's doing, although she often speaks of him when she sees Dr. L.

Did Dr. L. and the Beech Hill staff do the right thing in response to Mrs. C.'s bereavement?

COMMENTARY

Tony Yang-Lewis

The question of whether the truth should be told to a person with Alzheimer disease surfaces repeatedly on a daily basis. Sometimes the intent of a question is not necessarily to deduce facts but is a desire for reassurance to allay fear and anxiety resulting from memory loss and disorientation. If it is accepted that the Alzheimer patient's reality will not always match the caregiver's reality, then the caregiver could attempt to respond to the patient's anxiety rather than become embroiled in the facts that depend upon one perception of reality.

Yet when does that act of interpreting intent for another individual cross the line into duplicity that is expedient for the caregiver? Is the caregiver merely buying time until the question is asked again, or is he attempting to shield the patient from a painful truth? More importantly, when does that act on the part of a caregiver become presumptuous, a premature assumption that the individual's selfhood—and not just her memory—is eroded?

The decision to tell Mrs. C. the truth about her son's death may have been guided in part by a distinction between her consistent inquiries about Tony's health and general questions about orientation. Her interest in Tony's health surely preceded the onset of dementia, was based on facts in her life prior to her admission, and was clearly and consistently voiced throughout her stay at the nursing home. These were reasons to try to help her absorb this news information about her son, and indeed the staff's persistence, aided by the cue of the black dress, ultimately paid off.

Equally compelling was the desire of the Beech Hill physician to avoid requiring every staff member to collude consistently in a lie on every occasion that Mrs. C. asked about the welfare of her son. A colossal deception would have been introduced (and perhaps detected) in what had been hitherto an open and respectful relationship. Embarking on so large a deception would have required a fundamental revision in the staff's perception of Mrs. C., from a person with a disease to a person so diseased as to be inca-

pable of comprehending a momentous event in her life. Alzheimer disease has been stripping Mrs. C. of her short-term memory and has acted to isolate her reality. Deliberately withholding news of Tony's death could only serve to increase her isolation—not through the course of the disease but through the behavior of those closest to her.

Caregivers are in danger of further isolating that individual when they falsely assume that it is the disease that has eroded her capacity to assimilate or tolerate new information. To force the truth on a person who is delusional or has a markedly different perception of reality can be anxiety provoking and cruel. However, to deny a person the opportunity to assimilate information that is of paramount importance and meaning to her is to isolate and detach her from the very persons who can still help her to retain her sense of self.

One of those things that defined Mrs. C.'s sense of self was the fact of her relationship with Tony. It was therefore important for her to affirm the relationship throughout the natural course of his illness, even to its sad ending. The Beech Hill staff's response to her need maintained her selfhood. Their persistence was both humane and respectful.

COMMENTARY

Harry R. Moody

A fanatic has been defined as one who redoubles his effort, having lost sight of the goal. No more poignant example of fanaticism is imaginable than the devotion to abstract principle—truth-telling—revealed by this case. But history warns us to beware of sacrificing human beings on the altar of principle.

Bernanos once wrote, "The worst and most corrupting of lies are problems wrongly stated." But stating the problem in this case prompts more questions than answers. What sense really does it make to speak of *telling* the truth when the truth can only be *heard*, and then promptly forgotten, on a moment-by-moment basis? Does a patient's receptivity to truth count for nothing as we consider what might be the right course of action? Or have we become so frightened of charges of paternalism that we plunge ahead like fanatics in the name of truth-telling? What sense does it make repeatedly to put a mid-stage Alzheimer patient through the torture of re-living bereavement over and over again? How have we come to convince ourselves that such acts amount to "respect for persons"?

The nursing home staff in this case, like the torturers of the Spanish Inquisition, sincerely believe in the tenets of their faith, the ethics of rules and principles, despite their victim's anguish. Their practice is an image of hell or the myth of Sisyphus, where the demented person is condemned to suffer pointless repetition of pain. If the "Georgetown Mantra" were ever made into a philosophical faith, then this nursing home staff could be enrolled by

acclamation in the new priesthood. But woe to the victims of this philosophical faith, whose well-being must be sacrificed to the abstract creed.

Fortunately, a resolution in this case was found through a practical intervention of nonverbal communication. By introducing the black dress of mourning, the patient was finally able to remember and accept the finality of her loss. In this way the nursing home staff was able to make contact with whatever mysteriously remained of this patient's memory and understanding. Would the nonverbal technique alone have been sufficient at the outset? Was it necessary for the patient to be put through the torture of truth-telling before finding a resolution? There is no way of knowing for sure. We should not adopt the superstitious conclusion that because this combination of methods worked, it was therefore necessary to bludgeon the patient with the truth fifteen times. Perhaps a better route would be to experiment with a variety of communicative methods from the outset.

In clinical terms, this debate comes down to a clash between proponents of "reality therapy" (insistent truth-telling) versus "validation therapy" (going along with the patient's subjective reality). In a case like the one at hand, sustained deception should not be an option. Constructing a web of deception—e.g., "Your son is in Europe," "He's away, but he'll be back soon," and so on—is a dangerous tactic: the patient might one day ask, "Has my son abandoned me?" Systematic, repeated falsehood is bound to be corrupting in the life of any institution and in any case conspiracies are rarely leakproof. Such consequentialist, or better, prudential arguments have their weight. But they do not add up to a generalized endorsement of beneficence as an overriding principle. On the contrary, principlism as a methodology is what leads us astray in such matters.

Whatever decision is adopted in a case of this kind runs the risk of pain and tragedy. We can never be sure about the outcomes and therefore must not indulge the fantasy that we can control what measure of truth or falsehood will reach patients nor which messages they remember or forget. Both remembering and forgetting are unpredictable, in mid-stage Alzheimer disease no less than at other stages of life. The best approach is not to opt for abstract principle but to plunge into the tangled web of communication and keep all channels open (including nonverbal ones). A communicative ethic finds a place for principle as well as prudence. But above all it will experiment, being at once bold and humble in the face of the imponderable mystery of human interaction.