Dear Dr. Jeff:

Family members frequently express distress that the resident they visit is no longer the same person they knew and loved, while our staff seems better able to deal with the cognitive decline and behavioral changes often associated with advanced disease. How can we help families deal with both the grief experienced from a loved one’s decline and their guilt over their reactions to this decline? Is this even our job, or should they be seeking outside counseling?

Dr. Jeff responds:

When a daughter asserts that one of our residents is “not the mother I knew and loved,” she is not suggesting that her parent has been kidnapped by Martians and a substitute inserted in her place. Obviously, families accept, on a basic level, that the aging body has continuity with the younger, loved individual. Indeed, even though appearance changes, white hair and wrinkles do not suggest a different person, nor do amputations or facial paralysis. Functional losses — such as visual loss and orthopedic changes that prevent the individual from enjoying beloved activities like reading, knitting, or dancing — do not alter a family’s perception of the essential nature of the individual. However, as cognition and behavior transform with age and disease, many of the characteristics by which we define our loved ones do change. Families go through two grieving processes: the grief for the loss of particular aspects of personhood and individuality, followed by the inevitable grief over the actual cessation of breathing and heartbeat.

In contrast, quality care for the aged is centered on the goal of preserving the essential personhood of the individual as the mind and body decline. The Minimum Data Set obtains this one key element for every nursing home resident on admission: their prior habits and preferences. Times for waking and sleeping, favorite foods, bathing patterns, and typical activities and interests are all identified so that life in the nursing home can best mirror these preferences. The presumption is that the resident does remain the same person, despite losing many of his or her memories and living in a different set of circumstances, despite losing many of his or her memories and living in a different set of circumstances, the resident does remain the same person. The presumption is that the nursing home can best mirror these individual’s and preferences. Times for waking and sleeping, or cooperative. Unfortunately, the frontal lobe damage associated with dementia and decline of the brain damage from a stroke does not fully relieve the pain. Although grand- children can sometimes adjust to being mistaken for their parents (after all, we may look or sound like our parents), when a family member no longer recognizes our individual personhood, it may be more difficult to acknowledge theirs. One particularly stressful milestone occurs when the resident becomes unable to identify relatives. The child whose parent is unable to remember his or her name, or confuses him with a sibling or a stranger, feels emotionally orphaned. Intellectual recognition of the progressive nature of dementia often is also an acknowledgment of the continuity of personality despite neurologic decline. When we ask a family “what would your relative have wanted if they were able to tell us?” we are asserting a persistence of choices despite the resident’s altered ability to understand the current situation or formulate decisions.

She’s Not There

What are families really saying when they say that the person they loved is no longer there? Sometimes they are suggesting that various behaviors, usually those we may regard as problematic or undesirable, are not characteristic of the loved one they knew. In contrast, families are rarely distressed when they loved one’s personality change leaves them more relaxed, cheerful, or cooperative. Unfortunately, the frontal lobe damage associated with dementia often releases a variety of verbal and emotional outbursts that years of repression have kept bottled up. These can include colorful curse words, racial and ethnic slurs, physical expressions of frustration and anger, disinhibited expressions of sexuality, and indifference to cleanliness.

In her 90s, my wife’s grandmother (all 4’8” of her) tried to strike a nurse’s aide with a cane because the aide was preparing to put on the “wrong” shoes. I assure you that she would never have done that when she was in her 60s. Although some have referred to these behaviors as a “second childhood,” they certainly lack the charms of infancy and obviously include phrases (hopefully) unknown to children. Families will frequently say, “I didn’t know grandma even knew those words.” Obviously, seeing and hearing these behaviors can be both embarrassing and painful for the family. “That’s not my mother” becomes both a description of a behavioral change and an expression of denial.

Keeping Distance

These personality changes are often most difficult for children or other relatives who have not been involved in close contact or day-to-day care. These changes are usually gradual and often bring out aspects of personality that have been hidden from children or other relatives. Cumulatively over time, however, they can appear to be dramatic changes to the family member who visits only occasionally. Adult children often still retain an image of a wise, supportive, loving parent; this image may be more easily preserved at a distance. The role reversal that often occurs when parents and children transition into caregivers is painful under any circumstances but shocking when abrupt or intermit- tently experienced.

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She’s Not the Same Mother I Loved

Dear Dr. Jeff:

She’s Not the Same Mother I Loved

By Jeffrey Nichols, MD, CMD

What Can We Do for Caregivers?

What can we, as caring professionals, do to decrease caregiver suffering? First, we need to acknowledge and validate the caregiver’s pain. Witnessing the gradual decline of a loved one is, indeed, a torturous process. Simply listening can be therapeutic. But secondly, we need to assert the continued value of the lives of our residents. They are not “vegetables” and we are not gardeners or wasting our time providing care for those not worthy of our time. This assertion is particularly important because there is much that the concerned family can continue to do to improve the lives of their loved ones. Many of these are services that we can’t perform, so there is ample justification to try to keep the family involved in the nursing home rather than (or in addition to) referring them to the nearest therapist’s couch.

For example, although memory for names may be lost, the persistence of auditory memory means that residents may be pleased and soothed by family interactions and familiar voices. Even comatose patients show physiologic responses to loving expressions and encouraging phrases. Moreover, families can offer physical expressions of affection that are largely, by social and legal conventions, denied to our bedside staff. Physical touch from another human being relieves anxiety and reduces stress hormones. The elderly husband who simply sits at the bedside and holds his wife’s hand provides powerful therapy. The troubled daughter should be encouraged to kiss her mother and express her love.

Certainly education plays a role here as well. Families rarely receive useful information about the nature of dementia, such as prognosis, stages, and complications. Knowing what to expect — the course of disease rather than the details of Tau proteins and neurofibrillary tangles — may help to cushion the shocks as they occur. Nursing homes should offer family support groups that provide both education and opportunities to share emotional burdens. A relatively small investment of time can provide relief for the stressed family, reduce confusion over the reality of functional decline, and decrease the need for overworked and underprepared unit staff to explain behaviors.

Nursing homes frequently complain about problem families. Acknowledging these family issues and providing a gentle, guiding voice to support the grieving process are opportunities to prevent them.

Dr. Nichols is president of the New York Medical Directors Association and a member of the Caring for the Ages Editorial Advisory Board. Read this and other columns at www.caringfortheages.com under “Columns.”