

# WHAT KIND OF LOVE IS THIS?

*When memory fades, desire lingers on. Can nursing homes cope with their residents' sexuality?*

BY ATHENA H. MCLEAN



Paul Klee, Portrait of Mrs. P. in the South, 1924

**I**N ANOTHER TIME, IN ANOTHER PLACE, IT WOULD have been a simple romantic encounter. But here, in the ward of the Loving Sisters Nursing Home, it was not to be at all. Every day Carl and Vicki would stroll for hours, hand in hand, down the hall of their ward. Mary, hired by the family of another resident as a personal companion, was neither staff nor inmate, but she would seal the lovers' fate. Once her patient nodded off to sleep, Mary turned her attention to Carl and Vicki's liaison. Tonight, her antennae were aroused as the pair disappeared into Carl's room and closed the door behind them.

Mary stared at the door for several minutes, then walked over, opened it and went in. What she saw appalled her: Carl was standing near the bed, his pants dropped to his ankles, Vicki kneeling in front of him. Mary scolded the couple and ordered Carl to pull up his pants. Carl yelled at Mary to leave them alone, whereupon Mary rushed to the nurse in charge and reported her discovery. The nurse sent Carl and Vicki to their rooms and then questioned Mary about the event. On the basis of Mary's description, the nurse documented Carl's behavior as "agitation" and filed a report with the state.

Carl, who was in his early eighties at the time, and Vicki, who was then nearly seventy, both suffer from dementia—once known as senility—a debilitating, progressive and terminal disease, manifesting itself in short-term memory loss, disorganization and confusion; as it advances, it may result in an inability to recognize family members. Carl referred to Vicki as his wife, and though Vicki rarely spoke, the staff surmised that she thought Carl was her husband. But they were not married to each other. Vicki was a widow, and before her husband died, he and Vicki had walked together holding hands as she and Carl did now. Carl's wife still lived independently in an apartment, but after Carl had committed similar acts of philandering early in his dementia, she ceased all contact with him.

The head nurse's report led to a number of meetings between the administration, the staff and the families of Carl and Vicki. Upon hearing the latest report, Carl's wife authorized the home to use any means necessary—physical or chemical—to control him. In the eyes of the staff, Carl was the initiator of the affair and the less impaired of the two. But the important issue was not Carl's attempted adultery. The staff and administration were concerned about whether Vicki was too cognitively impaired to provide informed consent to the relationship and was thus vulnerable to sexual assault. Carl potentially threatened Vicki's personal rights, and the institution had an obligation to protect her.

A team of staff members and administrators decided to treat Carl's sexual conduct with behavior therapy. First they repeatedly showed him his wife's picture to reinforce that she—not Vicki—was his true wife. Then they placed him on a regimen of Mellaril, an antipsychotic medication and major tranquilizer, for his agitation, and Tegretol, an anti-convulsant, to reduce his "disinhibited" behaviors. But even after weeks of treatment Carl remained devoted to Vicki and would become upset whenever the staff attempted to ma-

neuver him away from her. At that point the staff decided to separate them permanently. They relocated Vicki to another floor, and they kept Carl on the dementia unit, where the open design afforded easier surveillance than did units with long corridors. He would be closely watched.

At her new unit Vicki became withdrawn and combative toward the staff. She was also placed on Mellaril to make her more manageable. Carl remained distressed and, perhaps as a side effect of the Mellaril, lost some motor control of his tongue. Those effects eventually subsided, and Carl started making friendly overtures toward other women in his ward. But neither Carl nor Vicki ever formed a relationship with others like the one they had shared.

**T**HE STORY OF CARL AND VICKI IS NOT UNCOMMON among the more than 1.5 million Americans—about sixty percent of whom suffer from dementia—now living in nursing homes. Stephen G. Post, a philosopher and biomedical ethicist at the Case Western Reserve Medical School in Cleveland, describes a similar circumstance in which a couple was separated by a nursing home. After the separation the man of the couple refused to eat or speak and eventually died from a "failure to thrive."

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Clearly, the simple expedient of separating people whose behavior is unpalatable or inconvenient to a nursing home or its staff can be disastrous for the residents of such institutions. And the need to develop more humane guidelines for dealing with such cases is becoming increasingly urgent as the population of the homes rises. In the past ten years that population has grown by 25 percent, and it will continue to climb in the next several decades. In twenty years the oldest of the

baby boomers will reach nursing home age; in thirty-five years, it is expected, the number of people over the age of sixty will approach the number of people under twenty.

Yet the traditional culture of nursing homes presents a substantial barrier to change. Although their proponents have long insisted that such facilities are indeed "homes," given the multiple, daily legal considerations that affect their operations, that description rings hollow. Restriction on sexual activity is only symptomatic of the protective bias that dominates the attitudes of many nursing home staffs toward residents with dementia. Carl and Vicki were victims of such restrictive practices, reinforced by staff politics and promoted by the institution's dependence on medical analysis for its rules and policies.

But guidelines based on medical ethics may be appropriate only for assessing medical needs; they may not be appropriate for emotional ones, such as whether a person is able to consent to a sexual, affectionate relationship. Determining what is best for people who are physically unable to care for themselves is a matter of some delicacy. But imagine yourself, in ten or thirty or fifty years, forced by age and incapacity to depend on the care of others for virtually all your basic needs. What would you want to retain of your emotional life? By introducing the concept of

“personhood,” which looks beyond physical and reasoning abilities to the person’s will and relationships with others, nursing homes could serve their residents more responsively and compassionately.

**A**S A CULTURAL ANTHROPOLOGIST, I FIRST VISITED the floor on which Carl and Vicki met while I was attempting to locate a dementia unit as a research site. Like many contemporary anthropologists, I had decided to apply the methods of anthropological fieldwork, developed by studying non-Western peoples, to learn about a culture close to home. My first reaction to the ward was one of shock. Here was a concentration of the bizarre—the extremes of ancient human beings—set apart from the rest of society. True, there were many who needed special care—whose bodies had to be moved, toileted, bathed and fed; but there were others who, though wheelchair-bound, were clearly here for other reasons.

In this ward, as well as in most of the home, privacy is at a premium. Rooms are never locked, doors are often left open, and the staff rarely knocks. Families sometimes hire personal companions—someone who is paid to give special attention to one resident—who often report their observations of the ward to the overworked staff. Mary, the personal companion who walked in on Carl and Vicki, did nothing out of the ordinary.

It was during my first visit that the head nurse on the unit told me about Carl and Vicki. She remained conflicted over the institution’s action. Although she had deferred to senior staff members who were more familiar with state regulations, the decision and its consequences had unsettled her. I spoke with the clinical team and members of administration, other staff and the families of the two residents in an attempt to reconstruct the situation. Nearly every staff member agreed that Vicki had always joined Carl willingly and had never exhibited any resistance to his advances. They also admitted that Carl and Vicki seemed to enjoy each other’s company. The other residents on the unit, perhaps because of their own loss of awareness, were undisturbed by the relationship.

Advanced age—as well as disease—has the power to transform people who once seemed wise and vital into distorted, sometimes unrecognizable versions of their younger selves. When that takes place, all the rules change. Nursing homes, in deciding how seriously to take a resident’s desires, place a high—and, I would argue, exaggerated—value on cognitive capacity: a person’s awareness of his surroundings and identity and his ability to reason.

Nursing homes test the cognitive capacity of their residents periodically. The test is made up of questions about the resident’s identity (“How old are you?”); general history questions (“Who was president during World War II?”); and simple figuring exercises (“Count backward from sixteen by twos”). There are also questions about the current circumstances: “What is the current year?” At the time of his liaison with Vicki, Carl could, at least, still take the test with some understanding, though his awareness of his sur-

roundings and his past was fading. Vicki, however, was beyond testing. She rarely spoke and gave little indication that she knew where she was.

When cognitive capacity has been so severely diminished, the wishes of residents are given little credence. In most matters—health, romance, personal freedom—nursing homes may rank the desires of residents, and especially those with dementia, below the needs of the families involved and below the needs of the nursing home itself. The home, one must remember, must protect itself from malpractice suits and state and federal regulatory violations.

The most popular way out of the nagging sense that the resident has been wronged is to rely on what medical ethicists call authentic or precedent autonomy. Every person to whom society grants such autonomy is assumed to possess an idealized moral agency. That agency is responsible for making decisions and for displaying a consistent pattern of habits and beliefs. The wishes and values of the “authentic moral self” are assumed to be fixed over time and across shifting contexts. Departures from expected behavior consistent with one’s past therefore become evidence of pathology; the misbehaving resident must, by the very act of misbehaving, no longer be capable of moral agency.

**B**UT IN MY VIEW SUCH AN OVER-MEDICALIZED approach, with its reliance on tests of cognitive capacity to assess the validity of residents’ wishes, dehumanizes and discriminates against those with dementia. Carl’s behavior toward Vicki was not seen as affection; instead, it was called disinhibited and treated with psychotropic medication. Affection and sexual desire were transformed into the by-products of a pathology, removed from Carl’s and Vicki’s moral agency.

A number of investigators, in contrast, argue that personhood cannot be as fixed as the proponents of authentic autonomy assume. According to the anthropologist Katherine P. Ewing of Duke University, people present themselves in multiple ways—in various selves that arise from identifications with significant people throughout life. Those selves are discontinuous from one to the other, and they vary with context, but people experience each one as a continuous whole. In a similar vein, Laurence R. Tancredi, a professor of psychiatry at the New York University School of Medicine, challenges the value of cognitive competence as the measure of social functioning and as a basis for deciding to abrogate elders’ rights. He suggests that such qualities as human connectedness to others are better indicators of functioning.

People with dementia may be unable to recall past events, but in most cases they are still able to reproduce meaningful relationships, because what is called “semantic memory” remains relatively intact. That memory is what enables people to assign meaning to what they experience in the present, unrelated to their personal history. According to the psychologist Karl E. Scheibe of Wesleyan University in Middletown, Connecticut, semantic memory makes it pos-

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sible for a person with dementia to interact in meaningful ways in the present, enabling them to recognize and reproduce cultural patterns. It gives people such as Carl and Vicki a way of creating a new self in relation to another person, thereby restoring a sense of continuity.

**T**HUS, INSTEAD OF CONSIDERING ONLY A person's cognitive capacity as evidence of an ability to consent to intimate relationships, nursing home administrators might try to evaluate relational capacities directly. Although cognitive memory is compromised in dementia, it may well be that affective—or emotional—memory is not. In a conversation, Vicki can forget what was discussed only minutes earlier, but she will respond with pleasure or distaste at the appearance of a nurse with whom she has just had contact. In dementia the ability to connect faces with feelings lasts far longer than the victim's grasp of relevant facts.

Nursing home residents, under the stress of their new living arrangements and the disinhibition that often accompanies dementia, may exhibit behaviors that depart from the norm for their age group, or even from their own behavior before the onset of dementia. A formerly shy person might suddenly feel comfortable singing in public, or a modest couple might display public kissing. (There have been rare cases of Alzheimer's disease in which the victim exhibited uncontrollable, inappropriate sexual desires—toward a son's or daughter's spouse, for instance—but those cases are not the norm.) But as alien as some new behaviors may be to the family and friends of the resident, they can be understood as new possibilities, rather than pathologies, that might ease the terrors of the isolation and fragmentation of dementia. Nursing homes should acknowledge and support—not block—residents' efforts to establish rela-

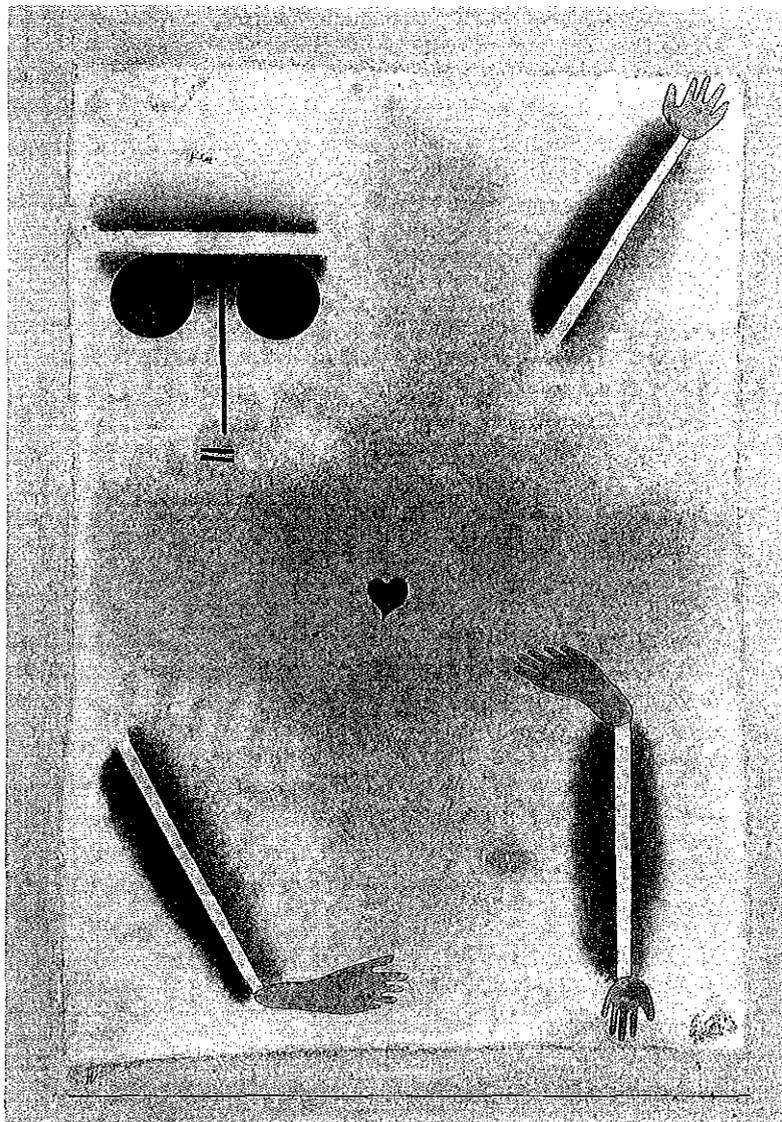
tionships in the present, their only remaining historical locus.

It is more than twenty years since the American physician Victor Kassel and the English psychologist Alex Comfort, formerly the director of gerontology research at the University College London, independently sounded warning bells about restricting the sexual lives of residents of nursing homes. But not much has changed. Given the sluggishness of institutions to change policies, it is never too soon to encourage them to develop alternative strategies that pay closer attention to personhood and the preservation of human rights and dignity.

**A**N INFANT becomes a person not only through biological maturation but also through social engagement with other people. And personhood is sustained only through continued recognition and the respect of others. New daily operating standards for nursing homes might enable them to meet the wishes of residents with dementia without abrogating their own responsibility to protect their residents from harm. Violations against personhood could be defined. Making fun of a resident, ignoring a reasonable request to be taken to the bathroom (to avoid an accident) or interfering with an affectionate relationship all could consti-

tute violations. One thing is certain: the curtailment of basic rights is unlikely to be acceptable to younger generations, who have come to expect a large measure of freedom and privacy in their personal lives. Yet if those of us not yet in nursing homes do not react until we are faced with their restrictions, we may well find, when the time comes, that we lack the power to challenge them. ●

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*Paul Klee, Has Head, Hand, Foot and Heart, 1930*