The Loss of Self

N ONE OF THE BETTER sections of Atlanta, a man in his early 60's again faces an anguished decision. His sister, 58 years old, has not been of normal mind for many months. Now, for the fifth or sixth time, she has smeared the walls of her home with feces. A neurologist has advised that she be admitted to high-quality nursing-home care, but the man is unable to bring himself to do that. Again, he increases the number of hours she is watched by a trained home attendant; has the walls cleaned; holds on. That same day, the neurologist interviews a 74-year-old man brought to the office by his son and daughter-in-law. The father, the examination reveals, is well and compos mentis, except for a mild impairment of memory. The young man says his father is independent, but he often forgets where he has put his shoes or his glasses. The young man has heard about the increasingly common ailment known as Alzheimer's disease, and would like to admit the older man "before the thing gets out of hand."

These cases represent opposite ends of a spectrum of real or suspected Alzheimer's cases. For Dr. Herbert R. Karp, a neurologist at Wesley Woods Geriatric Hospital, in Atlanta, and an authority on brain diseases of the elderly, the

first task in circumstances like these is to rule out medical or medication causes of dementia. (Dementia is the general term for loss of mental function, one cause of which is Alzheimer's disease.) These can include vitamin deficiency, liver disease, kidney malfunction or depression. Irreversible dementia is bad enough, but there is no sadder irony than the improper assignment of this diagnosis to someone who could have been rendered normal by correcting fluid balance, giving antidepressant drugs or even just discontinuing some medication.

Having ruled out such causes, exhausting the range of diagnostic tools, Dr. Karp proceeds to a treatment that medical school never trained him for, but that innate wisdom and a lifetime of medical practice have made almost second nature. Knowing the realities of life for the two patients, he will seek information about their relatives; how much resilience is there? How much patience? How much love? How much fear, because that, too, may lead to inappropriate action. In the first case, gently but firmly, he urges the brother to face the inevitable; he has more than done his duty to his sister, and his love for her - for the person he remembers - is standing in the way of the best possible care for her, even as it distorts his own life. In the second case, he sympathetically but decisively calms the young couple's immediate fears, and explains that the man's father may continue to lead a productive life. Various tactics at home can com-

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The causes
of Alzheimer's
disease, still
largely a medical
mystery, are
gradually being
uncovered by
researchers.

pensate for his memory problem and make life easier. To end his independence at such an early stage seems unnecessary and wrong.

Most of us will face these sorts of decisions. Although the exact prevalence of dementia — impairment of memory, language or other higher mental functions - is impossible to judge, the best estimates suggest that a severe form affects 4 to 5 percent of the United States population over 65, with an additional 10 percent of that age group suffering from mild or moderate impairment. This rate rises steeply with age. Among people over 85 - who now make up the fastest-growing segment of our population — the percentage of those severely demented reaches 15. With steadily increasing length of life, and given the presence at the moment of no major medical solutions, this much-feared disease is afflicting more and more of us. Few in years to come will be spared the pain of seeing a relative or close friend affected.

Unfortunately, modifiable dementia is the exception. In various studies, about 15 percent of dementia patients have been found to suffer from treatable conditions—caused by infections or drugs, for example. In a pathological study—one in which brains were examined in autopsies—20 percent of demented patients were found to

have irreversible damage due to hardening of the arteries caused essentially by fatty deposits. But fully 50 percent had, exclusively, Alzheimer's, a disease generally believed to be caused by two specific kinds of damage to brain cells; so did 65 percent of the residents dying in a nursing home.

Given how common it is, it is surprising that the disease was not identified until 1907. (One reason for the delay in accepting it was our prejudice that old people should lose their minds.) Alois Alzheimer, a German neurologist, studied the brain of a 56-year-old woman who had suffered from worsening disorientation and memory loss for five years. Under the microscope, he identified two signs that remain diagnostic today: "plaques," or large, dark bodies now known to be agglomerations of dead nerve endings; and "tangles," abnormally twisted tubular structures within nerve cells. The patient had an early onset form of the disease — there may be differences in the typical mental damage, depending on age — but plaques and tangles are characteristic at all ages.

Though mysteries still abound, we have in recent years made findings that go well beyond what Alois Alzheimer knew. First, there is a major loss of brain cells that produce acetylcholine, one normal chemical signal in brain circuits. These make up an important part of the cerebral cortex, or highest portion of the brain; thus the loss of memory, language and impulse control. Second, certain identifiable abnormal proteins have been found in the tangles and plaques; they may be the crux of the

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problem. Third, in some cases, the disease runs in families. There is no simple inheritance pattern; this may be due to different ages of onset. When some family members die of other causes before they are old enough to develop Alzheimer's disease, the line of descent can be difficult to follow. If you have one sibling who developed the disorder after age 70, your risk is no higher than that of the general population. On the other hand, if you had a parent and a sibling who both got it before age 70, your risk may approach 50 percent. A sufferer's identical twin is also at high risk.

Since 1987, the genetic explanation has received support from direct studies of DNA, the chemical stuff of heredity. The pair of chromosomes numbered 21 (among the total of 23 pairs in normal human cells) are abnormal in some families with Alzheimer's. People with the most common form of Down's syndrome, for example, have a triplet Chromosome 21 instead of a pair, and they typically develop Alzheimer's if they live into their 40's. Nevertheless, there have been many identical twin pairs in which only one twin had Alzheimer's. The environment may play a role, but precisely how remains unclear; exposure to aluminum and infection by slow-acting viruses are suspected as causes.

N THIS STATE OF IGNORANCE, PREVENTION and treatment elude us. Various drugs, and even diets, have been used in an attempt to raise the lowered level of acetylcholine, but the results have been minor at best. Recently, a committee of scientists was convened to consider the possible effectiveness of nerve-growth factor — a protein that promotes the development of brain cells under some conditions — in reversing the disease; but this idea is in its earliest stages of study.

What can be done in the face of this increasingly common, devastating illness? My first clinical tutor in medical school was a neurologist, and when I ribbed him about being unable to help many of his patients, he said: "If you want to be a fixer, neurology is not your field. But if you want to be a healer, consider it." By healing, he meant doing what you can to at least alleviate a problem even if you cannot really fix it. It is what Dr. Karp does on a daily basis with demented patients and their families. It means, among other things, distinguishing the dementia of Alzheimer's from reversible dementias; and distinguishing dementia caused by small strokes, which need not worsen. Having come to the conclusion that this specific condition is present, tests should then be done to document the declining brain function and to help the family determine what action to take.

Those range from formal tests in a neuropsychological laboratory to extended observations in the home. They make possible some other "healing" functions: prediction; support; explanation; encouragement; and critical aid in the tragic decision of whether to keep trying to care for the person at home. Not that the anguish ends with this decision. In medical school, I saw a woman in her early 40's — younger than Alzheimer's first patient — who in a few short years had deteriorated drastically in mental status. Her teen-age daughter, understandably, visited only briefly, and in a state of shock. But her own mother — 65 or so, tired and dreadfully sad — stayed in the hospital room all day every day, and sometimes all night, caring lovingly for the helpless child her daughter had once again become.

Someone recently asked me for an anthropological view on aging. I said one must be doubtful of reports of exotic cultures in which people are said live to be much older than 100; in fact, civilized cultures have the record. True, some hunter-gatherers may be more solicitous of their elders, but they have a lot fewer elders than we do. "How long do you want to live?" my questioner asked. My answer, without hesitation, is that I do not want to outlive my brain. The inevitable insults of the body's decay are bad enough. The least we have a right to expect from old age is mental life; tranquil wisdom that transcends childish impulse; verbal lessons for those who will outlive us; attachments that have meaning; above all, memories, without which we are very little. Simply because we don't yet have the keys to Alzheimer's doesn't mean we are not going to get them. We are just beginning to understand what causes these terrible transformations — but that is an important beginning.