

From the Editor

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From the Editor

**By Alison
McChrystal Barnes**

How I spent my summer vacation, Journal readers, involves the public health, infectious disease, the ostracism of those with frightening physical and mental conditions—and a big family wedding. Some people would think all of that is pretty scary stuff, and it certainly could be.

Again and again this summer, I saw the scenes through the lens of people with disabilities who must live apart to get care. Do you figure this kind of thinking is an occupational hazard? Some are left by their overwhelmed families to institutional care, to be visited once or twice a year in their semiprivate bedrooms. Others, in contrast, continue to be very much a part of the family.

It started when I visited Kalaupapa on the island of Molokai, where about 8,000 Hawaiians with leprosy were abandoned beginning in 1866. The cliffs on the north side of the island include the tallest in the world, over 2,000 feet to the sea. Kalaupapa, meaning “flat leaf”, is a peninsula of lava connected to the rest of Molokai only by a mule trail that requires about two hours’ travel each way. The descent, being so difficult, actually takes longer by mule than the climb.

Leprosy is a condition that is biblical for the horror it strikes in the onlooker, a terrible fate that tempts society to believe that the victim must somehow deserve it. This view of the cause of such an affliction originates, I think, in a wish to control and predict who must endure such a disease.

In 19th-century Hawaii, public-health officials had the force of fear behind their efforts to identify anyone with the disease. They identified men, women, and children who were examined without consent and ordered into isolation at Kalaupapa. The transport ships’ crews gave way to their fear as well, and refused to try to land. Instead, they threw their frightened human cargo into the shark-infested waters to swim for their lives to the sharp lava rock shore.

Those who reached the shore had more to endure. People with leprosy were confined to part of the peninsula with a deadly microclimate, always very cool, breezy and raining. Without materials to build shelter, the most common cause of death was pneumonia. Without principled government, only the strongest had the few goods the colony received from the ships. Even the strongest had too little food and no medical care.

What is the analogy with older people? First, that fear within our population causes many to shy away from elders who need care.

Aging, after all, is in its way more contagious than Hansen's disease (the more "respectable" term for leprosy), since most people of all ages and races will live to be old, maybe very old. In contrast, Hansen's disease is spread only by long-term and extensive physical contact with the germ, and only four to five percent of the world's population is even susceptible. Some in our youth-oriented culture apparently would say that looking really old is not much better than disease, and that the diminished productivity and dependency of advanced age are a terrible fate.

Second, isolation creates a community that is easily corrupted, in which might too often makes right. Thus, we have the recurring expose of abuse in nursing homes and other care institutions. The most recent examples were reported from Washington last August, and the local horrors are being reported this first week of September 2001. Even an institution with enough resources to provide good care can become a jail because there's no way out and no place to go. The residents, and even the workers, become the unhappy victims of their isolation and futility.

One person can make a difference, and in Kalaupapa that person was Father Damien, a Belgian priest who arrived in May 1873, just as efforts throughout the islands increased to apprehend and transport all with leprosy to the colony. Damien alone worked with the patients for fifteen years, building houses and churches, and tending to the sick and dying. He changed the colony from a desperate outpost to a functioning community. Schools were established for the children. The patients moved from Kalawao, the chilly east end of the peninsula, to the sunny western side where a fishing village was abandoned to their use. Three nursing nuns arrived in 1888, and their leader Mother Mariane Cope stayed until her death in 1918. A growing number of family members accompanied their spouses, parents, and children into isolation in order to serve as "kokua," helpers or caregivers.

Father Damien himself had only sixteen years to work. He was diagnosed with leprosy in 1885 and died in April 1889 at the age of forty-nine.

Kalaupapa has changed again by now, of course. Beginning in 1946, Hansen's disease could be treated with sulphone therapy. When the first six patients were treated, their condition improved virtually overnight. A new administrator recognized the era of cure by literally tearing down many of the physical

barriers that had always separated patients from non-patients. Many of those who were cured left the peninsula.

Others found that home and family were on Kalaupapa. No one was required by the state to leave the site of their compulsory residence, and those who stayed create the community of Kalaupapa today. It is still a place of intense isolation. Visitors can tour only with the guidance of a resident, and no new residents are permitted unless they are family members of one of the residents. No one can even visit overnight except at the invitation of a resident.

We toured with a resident I'll call John, and saw the town with its graveyards and aged cabins. Driving over terrible, pitted roads in an old school bus (because "those airport vans don't last six months out here"), we saw ancient Hawaiian sites with ruined dry stone temples, and reached the wild coast where a swimmer lucky enough to make shore would be cut up in crossing the sharp surface of the lava. Our guide was lively, opinionated, and voluble. He had come to Kalaupapa accompanied by a sister, and he bore the signs of the disease arrested many years before. He talked regretfully about how "we're all old here now." About the cohesive community: "If we had a wedding there would be people coming from everywhere, all the islands." He fed the mon-gooses (considered by some a plague because they have no natural predators) like someone who wants something to care for.

Of course, there were no children anywhere. A kid on Kalaupapa would have the doting attention of as many adults as a kid could want. Though a family member might arrive, few people are ready to move to a place where everything of any size must arrive on one of two supply barges in July or September. Mail arrives by plane or mule, but the daily small plane service was to be suspended because it is unprofitable. And every resident is at least seventy.

Although Kalaupapa is a national park of haunting beauty, it has also become an institution for its aging residents. The store, the library, the health clinic are heavily subsidized by the state of Hawaii, to allow those who want to stay to maintain any infrastructure at all. The residents are the tough survivors of an era that made them live apart because of society's fear and the lack of understanding of the nature of the problem and its management. They stayed because they loved the people they knew there, or they could not imagine anywhere else to live, or

simply because this place was home. They serve to remind us that isolating people shapes their lives and diminishes our own.

Fear of the obligations of care is the great burden of our aging society. Busy middle-aged adults, “sandwiched” between their aging parents and their growing, increasingly expensive children, need better ways to live with the responsibilities they bear. Women, our traditional caregivers, observed a generation or two ago that domestic efforts may fail to bring them an acceptable measure of security and appreciation, and have entered the market of paid work in great numbers. The home is essentially a part-time undertaking: evenings, weekends, and holidays at most.

On the other hand, few adults are entirely free of a sense of responsibility for the well-being of their aged parents, and of guilt if their parents live in want of care and attention.

A number of changes must take place before a satisfactory response to the need for long-term care can become widely available in the United States. One fundamental change is the development of a decently paid and respected workforce for institutions, as well as community-based care. A quality of generosity must underlie the provision of the simple services that typically keep an older person independent, rather than the current calculation of how little can serve to make a minimally acceptable quality of life. This is difficult to reconcile with an American “rights orientation,” which inquires how much one is entitled to. It is more compatible with a sense of community, and the individual calculation of whether enough has been provided.

A most difficult and important change, however, lies in ability of the care-providing generation to stay in close association with their elders as their capabilities fail. Employed adults who have had relatively light caregiving roles for a child or two—and who are beginning to sense the inevitability of their own aging—cannot shy away from helping, although their effect is limited. They cannot shy away from imperfect solutions to unwanted problems, or from their elders’ demands for dignified independence and angry, sad inability to act for themselves.

* * * *

Wow, time for a change of mood, though not a change of topic! I offer a wedding snapshot of people in the caregiver generation who have managed to encompass the lives of their elders in a remarkable way. The bride and groom met because their mothers live in the same nursing facility, Alzheimer’s floor. They took the moms out together for Sunday drives, good things to eat at the take out. Sure beats a bar for getting to know who somebody really is.

Last July, the moms came for the wedding, and talked or slept through the gathering of the guests. They were escorted down the aisle in their wheelchairs by the ushers—their grandsons—just before the bridal party. They really seemed to enjoy being part of it all. They were, indeed, just as they are and live, part of everyone’s event, and everyone’s awareness.

Alison McChrystal Barnes
November 2001

