
HEALTH

When the Last Patient Dies

Kalaupapa, Hawaii, is a former leprosy colony that's still home to several of the people who were exiled there through the 1960s. Once they all pass away, the federal government wants to open up the isolated peninsula to tourism. But at what cost?

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HUGH GENTRY / AP

Not so long ago, people in Hawaii who were diagnosed with leprosy were exiled to an isolated peninsula attached to one of the tiniest and least-populated islands. Details on the history of the colony—known as Kalaupapa—for leprosy patients are murky: Fewer than 1,000 of the tombstones that span across the village's various cemeteries are marked, many of them having succumbed to weather damage or invasive vegetation. A few have been nearly devoured by trees. But records suggest that at least 8,000 individuals were forcibly removed from their families and relocated to Kalaupapa over a century starting in the 1860s. Almost all of them were Native Hawaiian.

Sixteen of those patients, ages 73 to 92, are still alive. They include six who remain in Kalaupapa voluntarily as full-time residents, even though the quarantine was lifted in 1969—a decade after Hawaii became a state and more than two decades after drugs were developed to treat leprosy, today known as Hansen's disease. The experience of being exiled was traumatic, as was the heartbreak of abandonment, for both the patients themselves and their family members. Kalaupapa is secluded by towering, treacherous sea cliffs from the rest of Molokai—an island with zero traffic lights that takes pride in its rural seclusion—and accessing it to this day remains difficult. Tourists typically arrive via mule. So why didn't every remaining patient embrace the new freedom? Why didn't everyone reconnect with loved ones and revel in the conveniences of civilization? Many of Kalaupapa's patients forged paradoxical bonds with their isolated world. Many couldn't bear to leave it. It was “the counterintuitive twinning of loneliness and community,” wrote *The New York Times* in 2008. “All that dying and all of that living.”

The National Park Service, which designated Kalaupapa a National Historical Park in 1980, must decide what will happen to the peninsula once the last patient dies. If things go the federal agency's way, Kalaupapa would be fully opened up to tourists as outlined in a long-term plan that's been under development for several years. The “preferred” proposal, which is one of four that have been outlined by the agency as options, would lift many of the current visitation regulations that have kept Kalaupapa so remote.

Just a few dozen people live in Kalaupapa, including about 40 federal workers who concentrate on preservation efforts and a number of state health workers who oversee the medical side of things. (The state Department of Health director technically serves as the mayor of Kalaupapa; in late 2013, the director at the time died in a plane crash after an annual visit to the peninsula.) Current rules limit daily visitation to 100 adults, primarily through a single commercial operator that hosts guided historical tours. Children under 16 aren't allowed, and visitors must be invited.

The preferred proposal has caused significant consternation among various stakeholders—from Native Hawaiian advocates to Molokai residents to those with ties to the colony—who fear that the days of the Kalaupapa as they know it are numbered. The debates are further exacerbating political and cultural tensions in Hawaii, adding to the deeply entrenched skepticism among locals of outside

interests. Discussions about the future of Kalaupapa also come with a powerful, if painful, reminder about the difficulties of commemorating something that is understood so differently depending whom you ask. Over the past few years, I've spoken with a number of people intimately familiar with Kalaupapa, from conservation volunteers to leprosy researchers, and the one word that everyone used to describe the place is "sacred." For the most part, however, people struggle to articulate how Kalaupapa makes them feel.

Hansen's Disease—which is still most commonly known as leprosy—was extremely stigmatized around the world for centuries. (The name change was prompted in part by ongoing efforts to move past that stigma and is based on the physician who first identified the bacteria that causes it.) Described frequently in the Bible as repulsive and unclean, the disease was long feared to be highly contagious. Leprosy causes skin sores, nerve damage, and muscle weakness—symptoms that become debilitating if left unaddressed, but are now treatable with antibiotics. It's hardly as contagious as once thought, and as many as 95 percent of people may be naturally immune to the bacteria. Though it still appears around the world, including the U.S., it is close to being eliminated globally. A leprosy vaccine has been under development and was slated for its first clinical trials on humans this year. And yet ancient attitudes toward the disease have persisted.

Leprosy colonies, places where those who contracted the disease were isolated, were widespread during the Middle Ages, but they continued to crop up long after that—including a facility near Baton Rouge that was closed in the late 1990s. Steve Reder of the Infectious Disease Research Institute told *The Atlantic* in 2012 that isolated leprosy hospitals still exist. As tends to happen with disease outbreaks, including the recent Ebola epidemic, the ostracizing and hysteria surrounding leprosy were disproportionately directed at non-whites and other marginalized groups.

Kalaupapa remains eerily sheltered from the rest of the world even today. A common subject of small talk in the village is the one day each year that a barge lands with supplies, including gas and food, when the water is calm enough for it to dock. But Kalaupapa is as breathtaking as it is haunting, marked by white-sand beaches, coral reefs, and tiny bungalows that look as if they're frozen in time. It is, in some ways, a version of the Hawaii that was—pre-Waikiki, pre-World War II, pre-Five-0.

Many of Kalaupapa's memories are happy. Patients fell in love with and married each other; nearly 1,000 couples wed there between 1900 and 1930 alone, according to records compiled by the Kalaupapa Names Project. There were dances and musical performances, lei-making contests and softball games. Churches were popular gathering places, including one built by Father Damien, a canonized saint who contracted leprosy while living in Kalaupapa in the late 1800s. For many exiles, the Kalaupapa community—fellow patients, healthcare workers, clergy people—became their only family. Leaving the peninsula would become its own form of exile.

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After conducting an environmental impact statement and hosting a public-comment series, the National Park Service formulated its four alternative plans for Kalaupapa's future, two of which would open up visitation in accordance with specific goals and policies and one of which would implement zero changes. The federal agency explicitly prefers the alternative that would essentially establish a form of ecotourism: "Kalaupapa's diverse resources would be managed from mauka to makai (mountain top to the coast line) to protect and maintain their character and historical significance," the plan reads. "Visitation by the general public would be supported, provided, and integrated into park management."

The park's superintendent has said the intention is to retain "the sense of place and the feeling we have now" and emphasizes that little would change. Its people, she said, are the priority, as is its natural environment.

Still, it's easy to see why the issue is so fraught. Some are concerned that an influx of outsiders, particularly those who aren't sensitive to or familiar with Kalaupapa's past, would deteriorate the peninsula's spiritual ambience and undermine its historical legacy. Others worry about the risk this poses to the native flora and fauna, almost all of which are found no where else on the planet. After all, Kalaupapa is one of the last few truly untouched places in Hawaii, the world's most isolated archipelago and the home of a third of America's endangered species. Hawaiian politics are at play, too: Kalaupapa was home to Native Hawaiian populations for hundreds of years before the colony was established. Many stakeholders have criticized the historic failure to recognize that legacy and ensure Native Hawaiians special access rights to the land.

“There are so many restrictions now and I think that’s why the area has been able to be preserved,” Debbie Collard, a Kalaupapa nurse, recently told *Hawaii News Now*. “I would hate to see what we have here—the ability for people to come here and reflect and be able to have the memorial of their families here—for that to be taken away. I have such mixed feelings about all of it.”

Lindamae Maldonado, whose birth mother was a Kalaupapa patient, said the park service’s plan is “appalling” and would detract from efforts to gather and honor biographical information about the colony. The 66-year-old Maldonado, whose mother lived in Kalaupapa until she died a few years ago, only discovered her roots a decade ago. She stumbled upon the family’s story by chance, and grew up assuming she had a much simpler past based on what her adoptive parents told her. I met Maldonado a few years ago when reporting on family estrangement caused by the quarantine.

Maldonado’s discovery was both uplifting and heartbreaking, and she’s been trying to make sense of the confusion—and fill in the blanks on her new family tree—ever since the revelation. Though she was able to meet her biological mother a few years before she died and visited Kalaupapa regularly over the few years until then, their relationship, Maldonado says, was distant and bittersweet. They’d spend their time together watching Korean soap operas or women’s volleyball with other patients in the common room; they rarely conversed. Maldonado says she was taken into custody by health officials the instant her mother delivered her. She was then adopted by a Catholic couple who kept her Kalaupapa origins secret and whose names even appear on her birth certificate. It was when Maldonado was well into her fifties that she was told by an adoptive cousin about her birth mother. The cousin’s good friend turned out to be Maldonado’s biological aunt.

It’s the what-ifs that cause Maldonado the most pain. Thousands of children were probably born to patients in Kalaupapa, children who would grow up without a clue about their past because of custody laws and stigmatization. A state health official once told me that almost every woman quarantined in Kalaupapa gave birth there at some point.

And not only were children estranged from their parents—entire bloodlines were potentially erased. Maldonado, who is divorced and has three children, met her 76-year-old half brother from her father’s side just a few years ago. She and the brother,

Melvin Carillo, are now best friends, and Carillo even moved back to Hawaii in part to be closer to her. When I caught up with them a little over a year ago in Maldonado's small Oahu townhouse, she and Carillo held hands and completed each other's sentences, speaking of their upcoming plans to introduce their children. "My other sisters and I would play together. I never had that with her [Lindamae]," Carillo had said then. "That's my baby sister. We never had nothing together. I lost that, all that—the playing, the caring, the sharing. There was none of that for me and my youngest sister."

Kalaupapa "is such an important part of history" with "questions that we're still trying to solve," Maldonado recently told me when I asked her about the new plans. Until Kalaupapa sees more closure, she said, "there aren't any answers for the place." At least not one that involves making it a tourist attraction. But what might real closure look like? Though Maldonado's family-mapping effort has its critics, including advocates who say it infringes on patients' privacy, the people most intimately connected with the place seem to agree that the current restrictions should largely be kept in place. Some say it's especially important to preserve its boundaries once the last patients die, as it would become even more difficult to assess how to best honor their struggle.

"We are—and you are not," Clarence "Boogie" Kahilihiwa, one of the last-remaining Kalaupapa patients, explained to *The Times* back in 2008. "Every time one person dies, we get less and less." And even though Kahilihiwa supports the proposed change—at least the idea of allowing children to visit—tourism isn't on his mind: "Come when we alive," he told *The Associated Press* earlier this month, speaking in Hawaiian Pidgin. "No come when we all dead."

Indeed, many community members acknowledge that opening Kalaupapa would serve to raise awareness and educate those who might not otherwise resonate with its history. The Diocese of Honolulu supports the park service's plan because it would allow Catholics around the world to travel to the one-time colony, which was home to two saints, including Father Damien. According to *Hawaii News Now*, officials say that thousands of Catholics would start traveling to the area to reflect and pray.

Still, larger sensitivities about Hawaii's preservation compound the Kalaupapa controversy. The islands have seen their natural landscape change substantially in recent decades amid rapid population growth, commercial construction, and

massive public projects. Seventy percent of the beaches on Hawaii's most-visited islands are undergoing long-term erosion, and nearly two-thirds of its streams are considered "impaired" by natural pollutants. Current infrastructure can't handle the population: Honolulu is the country's most congested city, topping Los Angeles, according to INRIX's Traffic Scorecard.

Development has resulted in some of Hawaii's most high-profile political battles and large-scale lawsuits—and disputes over Native Hawaiian land rights have often figured prominently in these debates. Native Hawaiians have suffered from discrimination since Western contact, particularly since the islands were annexed by the U.S. in 1898. According to some research, the Native Hawaiian population declined by 84 percent between the time the British explorer James Cook arrived, in 1778, and 1840, when some historical accounts even predicted the complete eradication of the Hawaiian race by the early 20th century. The ban on the Hawaiian language wasn't lifted until 1986, and today, according to census data, those who identify as at least part Native Hawaiian constitute just a fifth of Hawaii's population. Yet they make up nearly 40 percent of the state's prison population and suffer from poverty at disproportionate rates.

“With the patient population getting smaller, there has been a tendency lately to refer to a time in the near future at Kalaupapa when there are no more patients,” the Kalaupapa advocacy organization, Ka Ohana O Kaluapapa, told the National Park Service in 2009. “The Ohana does not believe such a time will ever come to be. While the patient population may no longer be with us physically, they will always be present spiritually. They will always be part of this land.”

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