The forgotten dead

The AMHI Cemetery Project is raising money to build a memorial to Augusta Mental Health Institute's lost souls – thousands of patients who died in its long history and were too often quickly forgotten.

by Kelley Bouchard

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AUGUSTA — A disturbing memory has haunted Karen Evans since she was a patient at the Augusta Mental Health Institute in the early 1960s.

Evans was 17 when she was diagnosed with schizophrenia and hospitalized for about a year. During her stay, a girl she knew only as Margaret confided that she was contemplating suicide.

Evans warned hospital staff. The next day, she discovered Margaret in her room, her head forced between the bars on the window. The window was shattered. Blood was everywhere.

"They took her away and I never found out what happened to her," said Evans, now 65. "It happened more than once while I was there, but she affected me the most. It felt to me that people disappeared overnight. That life could be dismissed so easily."

Nearly 50 years later, the tragic memory of Margaret fuels Evans' desire to establish a permanent memorial to the 11,647 people who died at AMHI during its 165-year history. The hospital, which closed in 2004, kept no apparent records of where deceased patients were buried, other than a hand-scrawled map of a few graves in a nearby cemetery.

Evans and other participants in the AMHI Cemetery Project, which culled the names of the dead from dusty ledgers and boxes of files, believe that some of the lost souls of AMHI were buried in unmarked graves somewhere on the hospital's 800-acre campus on the Kennebec River.

There are more than 300,000 of these forgotten dead at active and shuttered state psychiatric hospitals across the country, reflecting a time not so long ago when people with mental illness were viewed as society's castoffs.

The AMHI Cemetery Project has launched a campaign to raise at least \$50,000 to design and install a memorial on the AMHI campus. The group's effort is part of a national movement to restore dignity to those who died without recognition in the past and foster compassion for the one in five American adults who have some form of mental illness today.

In March, the memorial project received a \$10,000 lead donation from the Elsie and William Viles Foundation, headed by 97-year-old philanthropist Elsie Viles of Augusta.

Viles said she was moved to make a contribution after learning about the disregard that was shown to fellow human beings just down the road from her home.

"It's one of those things that strikes you," Viles said recently. "It's so sad that it happened, even though it was a long time ago. I think it's wonderful that this group has organized an effort to remember people the way they should be remembered."

'PASSED AWAY IN THE NIGHT'

The AMHI Cemetery Project started 12 years ago, prompted by Evans and led by Amistad, an agency in Portland that serves people with mental illness.

Evans had attended a mental health conference in Texas, where she learned about the prevalence of unmarked graves at U.S. psychiatric hospitals and ongoing efforts to recognize the forgotten dead in other states.

When an initial search of AMHI's records found no burial record, the group got special permission from the Maine Department of Health and Human Services to search hospital records dating back to 1840, when AMHI was founded as the Maine Insane Hospital. As the hospital campus expanded, buildings were added and common language evolved, the name was changed to Maine State Hospital and later, AMHI.

Researchers found 11,647 names of patients who died on the premises. In the early days, hospital staff would simply note in a daily journal that a certain patient had "passed away in the night." Of the estimated 45,000 people who were admitted to AMHI from 1840 to 2004, nearly one-quarter died at the hospital, according to an AMHI Cemetery Project report.

The disregard that psychiatric patients were shown in death reflected the way many were treated when they were alive. Until relatively recently, mental illness was misunderstood and feared by many. It was a shameful condition, viewed as the work of the devil or God's punishment for sinful acts. Patients were often committed with little expectation that they would ever be released.

When the Maine Insane Hospital opened in 1840, one of the first eight patients was a

24-year-old Augusta man who had been kept in handcuffs at the local poorhouse for several weeks, according to a 1965 history of the hospital. Another of the first patients was a 49-year-old Kittery woman who had expressed "erroneous views on religion" and who, it was thought, contracted her illness while caring for her mentally ill father and brother.

Early diagnoses often focused on socially unacceptable behavior, according to the cemetery project's report. Well into the 20th century, people were admitted to AMHI for conditions ranging from epilepsy to Alzheimer's disease.

As a result, the list of 11,647 patients who died at AMHI includes people who didn't have mental illness, according to the cemetery project's report.

Early treatments at the hospital included medieval measures such as bleeding, restraining patients in a "tranquilizer chair" and cupping — when heated cups were placed on the body, causing skin blisters that were thought to draw out poisons. Through the years, medical treatments evolved from opium to thorazine to lithium and included controversial insulin and electroconvulsive therapies.

The AMHI Cemetery Project has requested access to additional hospital records that were recently transferred to the Maine State Archives. Researchers still hope to find a comprehensive burial record, though there's no evidence that such a record ever existed.

A NATIONAL ISSUE

The National Association of State Mental Health Program Directors issued a position statement in 2001 calling for states to find, restore and memorialize lost grave sites near psychiatric hospitals.

The AMHI Cemetery Project is one of several groups across the country that have responded, including an alliance of mental health advocacy groups that's developing a National Memorial of Recovered Dignity at St. Elizabeth's Hospital in Washington, D.C.

In case after case, disregard for the dead is stunning.

The cremated remains of 668 patients who died at Hawaii State Hospital between 1930 and 1960 were found in the basement, stored in crumbling cardboard boxes. About 3,500 canisters of unclaimed ashes were found on storage shelves at Oregon State Hospital.

More than 400 patients were buried in unmarked graves at the former Northampton State Hospital in Massachusetts. And 1,994 patients at Toledo State Hospital in Ohio were buried beneath small, numbered markers that were eventually lost.

Perhaps the most disturbing case occurred at the former Central State Hospital in Milledgeville, Ga., where about 25,000 people lay in unmarked graves, according to Larry Fricks, chairman of the national memorial project.

"The metal markers were pulled up at some point to make it easier to mow the grass," Fricks said. "It's difficult to believe, but that's what happened."

Fricks estimates there are more than 300,000 of these forgotten dead across the country, but he said the number could be much higher.

Elsewhere in Maine, patients who died at the former Bangor Mental Health Institute, which opened in 1901, were buried at nearby Mount Hope Cemetery, according to John Martins, spokesman for the Maine Department of Health and Human Services.

Martins said records show the state purchased plots at the cemetery for patients who died at the hospital, now called the Dorothea Dix Psychiatric Center. However, the

hospital kept no comprehensive record of burials, so it is unknown how many patients died there, where individual patients were buried or whether the graves are marked, he said.

Gathering that information would require a search of hospital and cemetery records, as the AMHI Cemetery Project did for AMHI, Martins said. At its peak population in 1970, the Bangor hospital had 1,200 patients. Today, it has 100 beds.

AMHI'S LOST SOULS

Some of the 11,647 patients who died at AMHI were returned to their families and buried in hometown cemetery plots. However, the lack of records leaves open the possibility that some were buried in unmarked graves on the hospital campus or in paupers graves across Maine.

Some unclaimed patients also may have been used as cadavers for lab experiments at the Medical School of Maine that operated at Bowdoin College in the 1800s and early 1900s — a practice that was legal here and in several other states in the past.

Researchers do know where a few AMHI patients were buried. An undated, hand-drawn map found in the hospital's archives shows about 40 graves in the paupers' section of the Cony Cemetery, on the other side of Hospital Street.

All of the wooden markers are gone. Seven patient headstones remain.

There's William Rae, who was born in Scotland in 1829 and died at the hospital in 1860. Angie Jackson was 18 years old when she died at the hospital in 1888. Elmer Bradbury, who died at the hospital in 1889, is buried next to his wife, Mary, who died in 1877.

Peter Driscoll has spent hours walking in Cony Cemetery, trying to reconcile the graves noted on the small map with what's left of the burial ground. Driscoll is executive director of Amistad, the primary sponsor of the AMHI Cemetery Project.

Standing in damp grass, pointing out the few headstones that can be identified, Driscoll is obviously frustrated and bewildered by the search for unmarked graves.

"They are absolutely lost souls," he said. "It boggles my mind that we just threw people away. Having a permanent memorial will help put to rest the shame and stigma associated with mental illness."

CHANGING ATTITUDES

Nearly all 11,647 names of patients who died at AMHI were read aloud during an emotional, daylong, rain-soaked ceremony on the hospital grounds in 2005. Several names were removed from the list at the request of family members.

With permission from the Maine Legislature, the remembrance list is published in a book displayed in the lobby of Riverview Psychiatric Center, which opened on the hospital grounds in 2004. The list also is part of a hospital history posted on the DHHS website.

Patient care and deaths at Riverview are handled much differently in the wake of a 1990 consent decree that addressed crowding and care problems at AMHI, according to Mary Louise McEwen, superintendent of Riverview for more than three years.

Today, Riverview keeps detailed records of all patients, but few have died at the psychiatric hospital since it opened, Mc-Ewen said. There are several reasons for that. Riverview has few long-term patients because of an increased emphasis on community mental health care, McEwen said. A typical stay is 45 to 60 days. Riverview also has fewer patients in general — fewer than 100 today compared to more than 1,800 in the 1960s.

Also, unlike AMHI, Riverview has no nursing home for dementia patients and no infirmary for seriously ill patients.

McEwen said Riverview patients who become seriously ill are discharged and transferred to MaineGeneral Medical Center in Augusta, which has a psychiatric unit, as most hospitals today do. If a former Riverview patient dies at MaineGeneral, Riverview assists with notifying family members and making burial arrangements, she said. Riverview directly oversees only burials of patients who die at the psychiatric center. Three people have died at Riverview since it opened in 2004 — in 2006, 2010 and 2011, McEwen said. Two were claimed by family members and funeral arrangements were made elsewhere. The third was laid to rest in Augusta and the state paid \$3,400 for the burial site, grave marker and funeral home services.

"We're very sensitive to the whole situation," McEwen said. "We deal with the whole person, but we focus on mental health. When a patient arrives, we get a complete medical and social history. But sometimes people give us false information. Some people don't want family members to know they're here. We do what we can."

While modern attitudes and practices have changed, that still leaves the deaths of 11,647 former patients largely unrecognized.

For those involved in the AMHI Cemetery Project, it's clear that raising a permanent memorial to the lost souls of AMHI is as much about the present and the future as it is about rectifying the past.

For Karen Evans, it's also about offering hope to others who struggle with mental illness. She has managed to put decades of abuse behind her and today works as a mental health advocate and trainer. With good care and community support, she has been in recovery for a decade. She's resigned to the fact that she may never know what happened to Margaret, despite her efforts.

"Today, we have hope," Evans said. "It used to be, there was no hope. They told my parents I'd be in an institution my whole life. I have hard times still, but I haven't been in

a hospital in 10 years. Everybody has value. Each life needs to be honored, even in death."

Even Margaret's.

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