A Day at Carville: My Home—*Mi Casa*

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According to the poet Henry Van Dyke, quoted in *Gone From My Sight: The Dying Experience*, an analogy of death is losing sight of a large ship as it meets the distant horizon. This loss is conversely gained as other eyes catch a glimpse of the same ship coming toward them.[1]

Being diagnosed with Hansen's disease (HD), more commonly known as leprosy, has been equated to dying—watching everything familiar disappear, and then entering a different dimension and meeting strangers just as caring as one's own family and friends. On February 28, 1968, at approximately 7:15 a.m., nine hours after admission to Carville, I received my first nod from a fellow resident—and stranger at the same time—welcoming me to "our home." (People affected by leprosy are routinely referred to as "patients," even after decades of being free of the HD bacillus. Therefore, my preference is to refer to those hospitalized as "residents.")

HD forced my parents to authorize my admission, lasting eight years, to the only leprosarium in the continental United States, the Public Health Service Hospital in Carville, Louisiana. This forced separation brought me much grief, pain, and loneliness. However, it also introduced me to a new family and an infrastructure created by a Law of Silence—the practice of lawmakers and policy makers capitulating to fears of leprosy by refusing to tackle the pain of stigma. My definition of stigma is an act of labeling, rejection, or unexplained fear of a person. Stigma for me started at the moment I was diagnosed with HD and magnified as I was placed in a hearse for a 750-mile trip for treatment, viewed by my family as a trip to my grave.

The Law of Silence gave rise to injustices in this 300-acre facility, but it also opened the door for sufficient funding to build a small city. The hospital had a power plant, water plant, incinerator for trash, certified high school, two churches (Catholic and Protestant), recreational facilities (lake, golf course, softball field, tennis court, theater, and auditorium), patient's canteen, rapid transit system (elevated), covered walkways designed to escape the usually soggy soil, space for personal needs (bank, post office, barber/beauty shops, cleaners), libraries (public and medical), and a cemetery.

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Additionally, the segregation of people affected by HD made it possible to conceive unique ideas for the formation of clubs and organizations chartered at the hospital, but linked to a larger bureaucracy located outside the hospital grounds. Some of these organizations included American Legion Post #188, Point Clair Lions Club, Patient's Federation, Mexican Club, and voting precinct #2 (Congress denied residents voting privileges until 1949).

Due to the HD bacillus, Carville became my home—*mi casa*. Admission to Carville always started at this unique community's hospital, or infirmary, mostly staffed by nuns with nursing degrees, from the Order of the Daughters of Charity. After a person's medical condition was stabilized by a team of physicians, then the nurses, physical therapists (PTs), occupational therapists (OTs), and another team addressing psychosocial issues (social and rehabilitation workers) would follow.

This second tier of workers focused on assigning dorm-like rooms with community baths, as well as matching a person's skills and interests with one of a multitude of jobs created for residents. Activity was an important part of hospitalization, as work could assist with the process of physical and spiritual healing, generate a small income for residents, and contribute to the continued existence of the infrastructure—e.g., janitorial services, aides, messengers, clerks at the canteen, librarians, or drivers.

So, after spending many months as an "inpatient" in the men's infirmary, I was assigned a room in the House 23 building. This building was constructed in the 1920s and was home to eight men who were in their fifties. Considering that I was the youngest person at the facility in 1968, these men were receptive to teaching me about the do's and don'ts of life at Carville.

I returned to the infirmary 17 different times because of severe reactions to the explosive and unpredictable growth of the HD bacillus in my body. Luckily, I arrived at Carville at a time when physicians were experimenting with a cocktail of medications, which helped to lessen my physical disabilities. For years, my daily medications were a mix of Dapsone, Prednisone, Thalidomide, and Clofazimine.

My responsibility changed dramatically upon admission to Carville. I went from having my mother and sisters clean my room at home in Laredo, Texas, which I shared with two younger brothers, to me having to change sheets, clean a small sink, and mop and buff the tile floor—this was an expectation for all residents. Failure to maintain clean rooms resulted in lost privileges.

Getting up early was the norm at Carville, as the dining room, centrally located at the complex, promptly opened at 7:15 a.m. and closed at 8:15 a.m. Lunch was from 11:15 a.m. to 12:30 p.m., and supper was from 4:30 p.m. to 5:30 p.m. Each meal was announced by the ringing of a large bell. Rarely would residents miss the call of the bell, as only married couples had the resources to cook in their assigned cottages/apartment-like dorms.

Prior to being allowed the opportunity to continue my college education at Louisiana State University, my time was filled with PT, dental, eye, and OT appointments, reading and writing letters to my family and girlfriend, working at the local café, or canteen, and teaching English at the school. Residents came from all over the world, but one-fourth of them were from Spanish-speaking communities. As is the norm in most small towns, the most popular gathering spots at Carville were at the canteen and post office (located next to the canteen). Staff, residents, and outside visitors would gather throughout the day to share stories about letters received, the most recent winners of sports pots, and life in general.

In the evening, I would attend any number of meetings for the Lions Club (secretary), Mexican Club (social events coordinator), and Patient's Federation (elected office—Sports Director). If a meeting was not held, I would get a golf cart and play a few holes of golf, ride my bicycle around the complex, go fishing at the man-made lake, watch TV in a common area, play some pool with other residents, or view a movie at the theater (Tuesdays, Thursdays, and Saturdays). The canteen and library would close at 8 p.m., the TV room at 9:30 p.m., and the recreation room at 10 p.m.; thus, after-hours partying was limited.

During weekends, activity at the hospital would slow to a crawl as residents either stayed in their rooms to escape the heat and humidity of Louisiana, or left the hospital grounds on "pass" if they had a vehicle. My time was spent being a tour guide to visitors from all over the world. The tours were at 10 a.m., 1 p.m., and 2 p.m. The tours included a viewing of an 8-mm film, distribution of literature, a brief walking tour, a question-and-answer session, and, on occasion, a small tip. This job served as a stepping-stone to my eventual discharge and role as an advocate.

Sundays were a challenge for me, as Catholic mass started at 9:30 a.m. and never ended before 10 a.m., the start time of my first tour. My resolution was to attend mass, a calming time for spiritual healing and learning from other residents. I would ask the front gate guard to delay sending me visitors until 10:30 a.m. Time spent at Sacred Heart Catholic Church, built in 1934, was a time to lessen my loneliness, as I knew my

family and girlfriend were also attending mass on Sunday mornings. Unfortunately, different chalices were used to administer communion to staff and residents up until 1971, when I challenged this practice. The end result of challenging the status quo of using two chalices simply because of an illness was months of silent treatment from some staff and other residents. However, victorious thumbs-up were also directed my way by others who were tired of this unfair practice by the church authorities.

Supper on Sunday evenings included a lunch box, which was designed to have residents converge under the beautiful oak and pecan trees to socialize. What the planners of this supper did not realize was that the 400 residents were socializing every day, throughout the day. This socialization was done with something as simple as a nod of the head, or as complex as a tight embrace—residents' lack of sensation and a mindset of preventing injuries resulted in few handshakes.

Mi casa has been described as a very busy place by many of my fellow residents. However, there were many days of extreme loneliness, compounded by the unmerciful heat of Louisiana, monotony of activities, and lengthy separations from family and other loved ones. Our home was filled with opportunities to learn from 1,322 people representing 25 different languages and cultures. (The hospital complex had 400 residents, 900 staff, 20 nuns with nursing degrees, one Catholic priest, and one Protestant chaplain.) We bonded in a unique and special way as we all shared the common language and culture of HD.

Carville was closed in March 1999; however, anyone choosing not to accept a government stipend to leave Carville could stay. Hundreds were not given a choice, as burial outside the hospital grounds was not allowed; thus, their final resting place was at Carville's cemetery. As of March 2007, 16 residents, mostly in their late seventies and early eighties, continued to call Carville home.

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REFERENCE

1. Karnes B. Gone from my sight: the dying experience. Vancouver (WA): Barbara Karnes Books, Inc.; 1987.