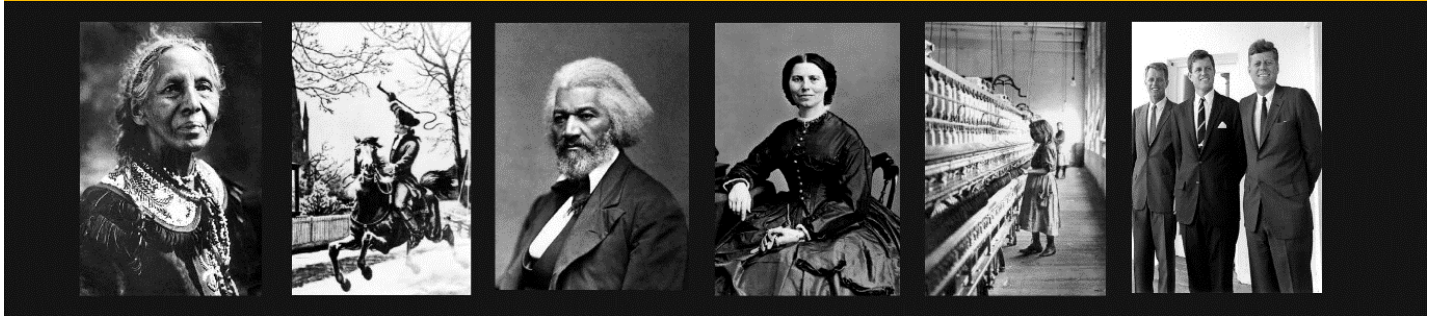


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The Rarely Seen Roosevelt

Very few photos exist that show President Franklin D. Roosevelt in his wheelchair or indicate the extent of his disability. Roosevelt contracted polio in 1921 but carefully concealed the full extent of his disability from public view. When Almena Clayton contracted polio in 1911, the Massachusetts Board of Health was concerned enough about the disease to issue an extensive report on its history, transmission and demographic impact. Undated photo.

Stricken: The Impact of Disease on Two Massachusetts Families, 1911–50

ANITA C. DANKER



Editor’s Introduction: *Before the social reforms of the New Deal, families struggled to manage the temporary or permanent disability of a parent or loved one largely on their own. This article explores how serious illness impacted victims and their caregivers in the first half of the twentieth century by focusing on the experiences of two immigrant women and their working-class families.*

In 1911, Almena Clayton (1884–1950) became ill with polio. Although her mobility would be compromised somewhat for the rest of her life, she recovered within a few years and was able to resume her former roles as wife, mother, homemaker, and, later, factory worker. In 1926, Alice Cardillo (1885–1944) developed mysterious symptoms that were eventually diagnosed as encephalitis lethargica, popularly known as the “sleeping sickness.” Her illness lasted eighteen years: she never resumed her normal responsibilities and was an invalid for many years before her death. Although nearly the same age, these two women, related by marriage, developed their illnesses at very different times in their families’ life cycles: Almena was only twenty-seven years old with young children to

care for, while Alice was in her early forties and the mother of young adult children when her mysterious illness began.

Themes of reliance, resilience, and shared identity emerged as powerful forces in shaping the individuals involved as they coped with family tragedy with limited economic means and within the constraints of their circumscribed worlds. Their struggles contribute to our understanding of how families during this era managed to adjust when a parent was unable, either temporarily or permanently, to carry on with household and child-care responsibilities.

The author, Anita Danker, is now retired after a long career in history and social studies education. She is related to the two Massachusetts families profiled in this study. An unpublished memoir written by the author's great-aunt furnished much of the information about Almena Clayton's battle with polio. Clayton was the author's maternal grandmother. The principal source for the story of Alice Cardillo's ordeal with encephalitis lethargica was a collaborative family history that Danker cowrote with a cousin based on interviews conducted between 2010 and 2014 as well as on vital records, documents, letters, and photographs. Cardillo was the author's paternal grandmother.

* * * * *

In the spring of 1911, a twenty-seven-year-old mother of three young children in the Boston suburb of Newton, Massachusetts, fell ill with a serious and puzzling affliction. A former laundress and millworker from French-speaking Nova Scotia, she lay in bed for six weeks, her skin pale and waxen, running a dangerously high fever and moaning in pain. Her rigid right leg was suspended in midair, attached to a wooden block hanging from a hook that her frantic husband, as directed by the local doctor, had hammered into the ceiling. Her husband and her twin sister, who left her own family in the care of neighbors and rushed to help, did their best to comfort the patient and her bewildered children, including a baby not yet a year old. The family doctor struggled to make a diagnosis, but Almena Clayton would learn only later that her weeks of acute pain, months of grueling recovery, and forever after shortened right leg were the results of polio, a viral infection that began appearing with alarming frequency in New England at the time.² Yet Almena would recover within a year and be able to resume her roles as wife and mother of young children.

Fifteen years later, another Massachusetts mother in the prime of her life was felled by a baffling malady after the birth of her eighth surviving child.

No family member seemed able to pinpoint exactly when Alice Cardillo's heartbreaking ordeal began. They recalled only that she did not recover after her last pregnancy, and she began to lapse into a pattern of extreme fatigue and endless sleep. Before succumbing to the mysterious illness, she had been the center of her devoted brood's universe, overseeing their lively activities in a sprawling Victorian home in the Dorchester section of Boston. They remembered her as a strict disciplinarian and a talented cook, preparing traditional Italian meals for them and the stream of visitors who appeared on weekends to seek advice on a variety of matters from their father, a respected member of the local immigrant community.

In contrast to Almena's relatively quick recovery, throughout the 1930s and into the 1940s, Alice spiraled into total helplessness, exhibiting signs of mental illness and losing the use of her limbs. In the end, she could communicate only by blinking. As with Almena Clayton, Alice's affliction was not initially identified by the doctors who attended her. However, family members needed no definitive label to recognize that their loved one was very sick and needed their care. They gradually learned to adapt as her health steadily deteriorated. After eighteen years of relentlessly worsening paralysis, Alice died at home.³

SIGNIFICANCE OF INDIVIDUAL FAMILY STORIES

The two women were not friends, but surely Alice and Almena knew of each other. Eventually they became in-laws. Through a double strand of marriage, with a Cardillo son and daughter marrying a Clayton daughter and son, their lives intersected. However, when Willie Clayton and Abbie Cardillo married in 1934, Alice was already ill. Six years later, Bob Cardillo married Edna Clayton. Whether Alice was able to attend either of these weddings remains unknown. Both families lived in the same section of Dorchester, although the Claytons moved frequently.

Their individual stories are important because they shed light on how two serious diseases that affected significant numbers of Massachusetts residents in the early decades of the twentieth century disrupted families before there was an effective safety net to provide the services that might have lightened their burdens. Their struggles contribute to our understanding of how families during the era managed to adjust when a parent was unable, either temporarily or permanently, to carry on with household and child-care responsibilities.

In the shadow of the devastating influenza pandemic of 1918, polio and encephalitis lethargica were pushed to the background, and, in the case of

the latter, nearly forgotten. Consequently, the Clayton and Cardillo children never fully recognized the historical significance of their mothers' illnesses, yet both families were indelibly shaped by them. In the case of the Cardillos, the siblings learned to pull together and as a result developed a shared identity as a special family that successfully met the challenge of caring for a disabled parent. The Clayton children, on the other hand, were too young to shoulder the responsibility of managing the household and comforting their mother during her acute illness and slow recovery. It was the adults in both their nuclear and extended web of kinship who marshaled their resources to steer the family through the crisis. In both cases, the themes of family reliance and resilience emerged as transforming forces in shaping their identities.

The serious illness of a spouse or parent is a major life stressor for any family. Researchers have investigated the topic from a variety of perspectives — those of the children, the spouse, and the family as a unit. They have developed models to explain how families cope and adapt to stress, both ordinary and catastrophic.⁴ They have parsed the concept of family resilience when the former caregiver is incapacitated due to chronic illness.⁵ They have investigated how children evolve from dependents into caregivers.⁶ And they have created blueprints for families in crisis concerning how to endure and thrive.⁷ Most of this research was conducted long after Almena and Alice were stricken with life-altering medical conditions. Still, much of the work of social scientists in the latter half of the twentieth century and beyond is relevant to the situations in which the Clayton and Cardillo families and countless others of limited means found themselves during an earlier time.

POLIO FEARS IN MASSACHUSETTS

Well before the historic epidemics of the 1950s, polio had been a serious health concern that baffled the medical community in the United States.⁸ Though not as deadly as a number of other diseases common during the era, such as influenza and tuberculosis, it was nonetheless a major public health issue. The seemingly erratic nature of its reach, the fact that it appeared to target healthy children, its debilitating aftereffects that sometimes included dependency on a respirator or iron lung, and a lack of understanding as to its cause, spread, and effective treatment were issues that medical researchers and practitioners struggled to address. A 1916 outbreak of polio in New York City and the fact that Franklin Roosevelt, who would go on to become governor of New York and later president of the United States, was felled by polio in 1921 heightened public consciousness of the disease prior to the near panic of the 1950s.

The earliest polio epidemic on record in the United States occurred in 1894 in the Otter Valley, not far from Rutland, Vermont, a rapidly developing community due to the demand for marble from its nearby quarries.⁹ Thanks to the diligence of the local doctor, Charles Caverly, who treated many victims and carefully described their symptoms, the medical community at large learned of the outbreak. There were over one hundred victims, mostly young children, the majority of them male. Many were left paralyzed for life, and eighteen died.

In Massachusetts, by the time that Almena Clayton was stricken with polio in 1911, the State Board of Health was concerned enough about the disease to issue an extensive report on its history, transmission, and demographic impact. In the introductory essay, James Warren Sever, a surgeon and orthopedist at Boston Children's Hospital, claimed that the increase in cases of polio in North America in the early years of the twentieth century coincided with the arrival of unprecedented numbers of European immigrants who had settled throughout the country during the period.¹⁰ Sever contended that the newcomers were most likely the source. In his overview, he noted that while not of epidemic proportion, signs that polio was striking more frequently began to appear in Boston as early as 1893, when twenty-six victims were reported during the summer months. Typically in earlier years, there had been fewer than ten.

By 1909, polio was a reportable disease in Massachusetts, meaning that physicians who diagnosed and treated its victims, were required to report it to the State Board of Health. In 1910, polio was observed in dozens of towns throughout the Commonwealth. Springfield and Fall River were especially hard hit. Clearly, polio was on the rise in the state.

The Massachusetts Board of Health noted that during the 1907–1912 time span, communities located near riverbeds were most vulnerable to polio outbreaks.¹¹ Such observations supported the commonly held belief that polio was spread, not by direct contact with infected individuals, but by insects that bred during the warmer months in the state's many bodies of water.¹² Although this conclusion later proved to be erroneous, it was a logical one based on the prevalence of polio outbreaks during the summer season. Towns along the Hoosic, Housatonic, and Deerfield Rivers in the western region as well as the Merrimack in the east were especially hard hit during the years under investigation. The report also mentioned that in view of the fact that some communities identified only a few victims during the most serious outbreaks, infection by contact with third parties was rare, as was the appearance of new cases in the years following an epidemic in a particular locale.

In a paper prepared by the state inspector in Springfield, physician Herbert C. Emerson explored in depth a number of topics related to the sixty-nine cases that were reported in his district in 1908.¹³ He investigated such factors as the weather in the region, the geographic distribution of those afflicted, and the diets, ages, gender, preceding illnesses, symptoms, and recovery of the patients. The majority of the victims were children or young adults.¹⁴ Most commonly their symptoms involved pain, fever, nausea and vomiting, constipation, and stiffness of the neck or spine. There were five deaths in the cohort studied by Emerson, and four individuals who made only slight improvement in the various types of paralysis that they endured. Six of those who were stricken recovered completely, while the rest showed only partial improvement. Emerson concluded that infantile paralysis was an infectious disease but only mildly contagious. The cause was unknown but appeared to be a “harmful agent” that entered the body through the digestive system.

POLIO: EARLY TREATMENT

The treatment of polio in its acute and recovery stages during the later epidemics of the midtwentieth century was clearly influenced by polio survivor Franklin Roosevelt, who served as a role model for other victims, and the establishment of Warm Springs as a preeminent rehabilitation facility in Georgia. The launching of the National Foundation for Infantile Paralysis (NFIP) in 1938 and the innovative methods popularized by Australian nurse Elizabeth “Sister” Kenny and her centers, which relied on hot packs and stretching affected muscles, were additional weapons in the fight to conquer infantile paralysis.¹⁵ In Massachusetts during the earlier era when Almena Clayton was stricken, much about the disease was still unknown, and treatments somewhat speculative. However, the standard practices did not differ in many significant aspects from those followed during the later period.

Boston physician Robert W. Lovett, who would be called upon in the summer of 1921 to confirm Roosevelt’s diagnosis, contributed the concluding essay to the Massachusetts Board of Health’s 1914 report on infantile paralysis. In it, he outlined the best practices of the day: quiet bed rest, light meals, and efforts to keep the digestive system functioning normally during the acute phase.¹⁶ He advised caregivers to leave the recovering patient alone in the immediate aftermath of pain and fever and while there was still tenderness in the limbs, except for helping him or her change position, bathe, or relax outdoors. Lovett suggested massage and the retraining of muscles once the patient could tolerate such treatments, and he recommended surgery as a

**NEW DISEASE A
NATIONAL PERIL**

**Hundreds of Cases of Infantile
Paralysis Reported From
Different States.**

MANY CASES IN CANADA, TOO

**Large Number of Deaths Followed
the Attack of the
Disease.**

Special to The Star.

Washington, Oct. 3.—Infantile paralysis, in low numbers, its victims in all parts of the country, presenting a national peril, according to reports made public today by Surgeon-General Walter Wyman, of the Bureau of Public Health, Government experts are engaged in researches to discover a cure for the mysterious disease. In order to get information that might be useful in this work General Wyman sent a request for reports on the subject to secretaries of State and Territorial Boards of Health.

During July eighteen cases and two deaths were reported in six Connecticut towns.

The Pennsylvania Commissioner of Health stated that in July there were 152 cases, and from August 10 to 15 the cases reported numbered 16.

This year there have been 57 cases and 19 deaths in Kansas; in Iowa 140 cases and 29 deaths; Massachusetts, 200 cases; Minnesota, 20 deaths; District of Columbia, 71 cases; Rhode Island, 82 cases; Washington, 110 cases and 70 deaths; and Oklahoma, 5 cases, 4 deaths.

Many cases have also been reported in the Niagara Peninsula, in Canada, and at Hamilton and London, Ont.

“New Disease a National Peril,” *Toronto Star* (October 3, 1910)

The article refers to “hundreds of cases” of polio reported in the U.S. and lists 26 cases in Massachusetts.

last resort, only to “correct fixed deformity” or to “secure stability of useless joints.”¹⁷

In the first decades of the twentieth century, the medical establishment in the United States, to which Lovett and the other practitioners investigating polio belonged, was still in its fledgling period. Long eclipsed by the Europeans, particularly the Germans, American medicine was finally coming into its own. While the woeful state of medical care during the nineteenth century, particularly during the Civil War is widely known, what is less well publicized is the fact that American medicine continued to lag behind for many years after. In providing a context for the flu pandemic of 1918, author

John M. Barry argued that for the most part, American medical schools were more concerned about financial stability than in enforcing stringent entrance requirements or imposing a rigorous curriculum. He claimed that many “bestowed a medical degree upon students who simply attended lectures and passed examinations; in some, students could fail several courses, never touch a single patient, and still get a medical degree.”¹⁸

The founding of a medical school at the relatively new Johns Hopkins University in Baltimore in 1893 was the catalyst that revolutionized how American physicians were educated and trained for practice. By the time of the great influenza epidemic during World War I, the medical establishment in the United States had caught up to its European counterpart and “was about to surpass it.”¹⁹ While it is impossible to know if the unnamed physicians who attended to Almena Clayton during her ordeal with polio were trained in the methods disseminated by Hopkins and soon adopted by Harvard and other leading universities, it is clear that her treatment followed a pattern similar in many aspects to that described as standard in the epidemics of the midtwentieth century.

ALMENA CLAYTON’S LIFE BEFORE POLIO (1884–1911)

Born to a hardscrabble family in D’Escousse, Nova Scotia, in 1884, Almena Bissett was a delicate child whose early years were unsettled and often difficult. She was the frail identical twin daughter of Alfred Bissett, a fisherman and jack-of-all-trades of Scottish ancestry, and Irma Maguet, whose background was French. Maguet was a single parent with two young children at the time of her second marriage. A bride at the age of fourteen, she was widowed at seventeen when her first husband was lost at sea, and she went to live with her younger siblings and her mother, also a widow and something of a legend in the community due to her skills as a nurse and midwife. The two widows scraped together a living by taking in laundry, ironing linens for the parish priests, gardening, and tackling whatever odd jobs they could find to survive.²⁰ As recounted by family members, Maguet met Bissett, a sailor fresh from a stint at sea, when he stopped at her cottage looking for someone to do his wash. After a brief courtship, the pair married and had two more children before the twins were born.

When the babies were just six months old, the Bissetts relocated temporarily to Massachusetts in search of economic opportunity, leaving behind Emma, the sturdier of the pair. Because Almena needed constant care, her mother thought it best to keep her close by her side. Two years later, the family returned to Nova Scotia, where the twins reunited and

became inseparable. In 1889, when the girls were five years old, their parents decided to move back to the United States, where some of the older children had already settled. Looking for more stability than afforded by a life at sea, Bissett established a painting business in Newton, Massachusetts, with his youngest son. Upon their arrival in New England, Almena and Emma enrolled in a Catholic grade school, enjoying their status as identical twins, whom even the nuns teaching them could not distinguish. The family continued to struggle financially and began to take in boarders to help pay the bills. After six years, homesick and still poor, the Bissetts gave up their boardinghouse and returned to Nova Scotia.

The pattern of instability continued for the Bissetts as the twins grew to young adulthood, and the two soon moved back to the United States, where they found work in factories and laundries as was customary for young women of their background. In 1904, at the age of twenty, Almena married a clever mill hand originally from Lowell, Massachusetts, Richard Clayton. Her occupation, as recorded in the marriage register, was laundress, the same path followed by her mother and grandmother before her. The newlyweds settled in Newton, familiar territory for Almena. The Clayton family expanded with the births of two daughters and a son by the time Almena began to experience the debilitating symptoms that her family doctor initially diagnosed as sciatic rheumatism. (Medical practitioners at the time commonly labeled as rheumatism any number of painful maladies they could not explain, including arthritis, sciatica, and polio.)²¹

ALMENA'S BATTLE WITH POLIO, 1911

Almena became gravely ill in the spring of 1911, when her youngest child was not yet a year old. She took to her bed with a high fever, extreme fatigue, and excruciating pain that became localized in her right hip, leg, and foot.²² She moaned constantly and cried out if anyone tried to touch her. The family was in disarray, as her exhausted husband, who worked long hours at a mill during the day, tried to manage the laundry and cleaning when he came home at night. Relatives and neighbors looked after the toddler, while Almena's sisters, Josephine and Emma, did their best to provide nursing care as directed by the local physician. He suggested that Richard build the wooden block contraption described earlier for the purpose of keeping his wife's rigid leg stretched and suspended in midair. For the pain, he ordered those attending Almena to pour a solution of ten percent ether onto a cloth and pass it back and forth under her nostrils. He also advised them to play soothing recordings on the "talking machine" to help keep her calm. The



Life Before Illness

This photo shows a young Almena Clayton in the early 1900s.

treatments brought little relief, and, about six weeks after the onset of the symptoms, the family doctor decided to send the patient to the hospital.

The Clayton family did not record the name of the facility to which Almena was sent, but the nearest one would have been Newton Hospital, later Newton-Wellesley, which was established in 1880 as a small local or cottage hospital and steadily expanded to include a clinic and an orthopedic unit in 1910.²³ Once hospitalized, Almena received treatment similar to what her family had provided at home. Rather than keeping her painful leg suspended by a device in the ceiling, however, her physicians ordered that



Almena Clayton at Midlife

This photo shows almena clayton in the 1920s, after her recovery from polio.

a heavy weight be attached to her ankle with wire and allowed to hang to the floor. Although her fever continued to rage, she grew no worse. With the bills mounting and little signs of progress after months in bed, Almena was advised by hospital staff to consider going to a relative's home where she might gradually regain her strength and eventually recover.

Her husband, Richard, and sister Emma consulted and came to the conclusion that the best place for Almena was back in D'Escousse, Nova Scotia, under her mother's care. While the initial decision was not difficult, working out the details was a challenge. First they needed to persuade

Madame Bissett to consent to taking on such a daunting responsibility and then to strategize the logistics of transporting the patient safely. The trip from Newton to D'Escousse was nearly eight hundred miles. They agonized over who would care for the three young Clayton children and wondered if Richard would ever be able to pay the mounting costs — the medical bills, railroad fare, and household expenses — on a mill hand's salary. Eventually, the family worked out a plan, and Almena's mother agreed to travel to Massachusetts by rail to take Almena and all the children back to D'Escousse. Richard would break up his household and remain behind so that he could continue to work and meet ongoing expenses.

There were few alternatives for families in situations such as the one in which the Claytons found themselves in 1911. Working class individuals disrupted by illness and other misfortunes relied heavily on their relatives and friends, private charities, churches, and the community to provide a lifeline. In Almena's case, Emma, ever the resourceful optimist took up the cause and became convinced she could help finance the family's transportation expenses by holding a fundraiser — a benefit whist or card party “as they were still the rage.”²⁴ She obtained permission from the parish priest to use the church basement for the social, arranged for tickets to be printed, and then cajoled everyone she knew into purchasing one or more for fifty cents apiece. The plan was a success, and Emma raised sufficient funds to cover expenses and to allow Richard to take a two-week leave from work to accompany the travelers and help them get settled in Nova Scotia.

To protect her right leg during the journey, Almena, who was still immobile, wore a brace that attached to an iron ring around her body. It had to be custom made because she was so small due to all the weight she had lost during her ordeal — an added expense. The Claytons were able to secure a private compartment on the train to D'Escousse, large enough to accommodate their party of three adults and three children. Railroad personnel were compassionate; porters carried the patient with all her heavy medical accessories and made sure she was safely settled in her temporary quarters. The first part of the trip, from Boston to Mulgrave, Nova Scotia, was the most comfortable. Once the party disembarked at the railroad station, they still had over one hundred miles to travel by sleigh to the remote village where the Bissett home was located. They arrived in a snowstorm to anxious relatives, unsure of how their loved one's recovery would unfold. Through the efforts of her extended family in Nova Scotia, Almena slowly improved, but, as was the case with so many victims of polio, she was left with a shortened leg and diminished mobility for the rest of her life.

THE SLEEPING SICKNESS: ENCEPHALITIS LETHARGICA

Unlike polio, encephalitis lethargica, the disease that felled the matriarch of the family whose destiny became interwoven with Almena Clayton's, had no famous victims the stature of Franklin D. Roosevelt, no Warm Springs, no highly publicized March of Dimes campaigns. Although thought to have surfaced from time to time throughout history, encephalitis lethargica, or von Economo disease, or the sleeping sickness, appeared in epidemic numbers in the United States in the aftermath of the 1918 influenza pandemic and was to some extent a neglected medical phenomenon. Speculation at the time held that the strange malady was somehow related to the virus that caused influenza.

The symptoms were so diffuse and similar to those associated with other diseases such as meningitis and polio that diagnosis was difficult.²⁵ The relative anonymity of the disease changed somewhat in the 1970s due to the research and subsequent publications of British neurologist Oliver Sacks, whose memoir *Awakenings* became a bestseller and the basis for a well-received motion picture. In the late 1960s, Sacks was working at a hospital in New York City when he encountered a neglected group of survivors of the post-World War I epidemic of encephalitis lethargica. Suffering from Parkinson-like symptoms, some responded favorably to an experimental drug, L-dopa.²⁶ Though the drug proved disappointing to Sacks, at least in his initial hope that it would be a cure for chronic postencephalitis patients, it did help alleviate symptoms in some and may indeed have "had more lasting beneficial effects than originally thought."²⁷ Sadly for Alice Cardillo and her family, the work of Sacks and others came too late to help them through their eighteen-year ordeal to understand the relentless and baffling encephalitis lethargica.

The disease was first described in modern medical literature by Constantin von Economo, a neurologist and psychiatrist who was working at a clinic in Vienna in 1917 where he observed a number of individuals who presented a series of bizarre neurological symptoms.²⁸ While most of his patients were soldiers returning from the front with head wounds, one strange case surfaced involving a civilian who could not stop falling asleep. Several similar admissions followed, and, although the symptoms varied, nearly all exhibited sleep disorders, malfunction of the eye muscles, and extreme fatigue.²⁹ Von Economo hastened to deliver a paper at the 1917 meeting of the Vienna Psychiatry Society at which he claimed to have identified a new disease.

While the specific origin of encephalitis lethargica has never been determined, and the symptoms may vary, those writing about the medical mystery describe a set of defining, albeit sometimes contradictory, characteristics.³⁰ In the acute phase, patients all experienced sleep disturbances, mostly somnolence, although

some suffered from insomnia. Frequently, they complained of headaches, vertigo, difficulty swallowing, tremors, and weakness of facial muscles. Digestive disruptions and loss of taste and weight were commonly reported. Some victims became delirious, intellectually impaired, depressed, and/or emotionally disturbed. Some hallucinated. About fifteen percent of those afflicted died during the acute phase of encephalitis lethargica. They may have been among the more fortunate victims.

In Massachusetts, encephalitis lethargica was added to the list of reportable diseases in 1921.³¹ As with the official state reports on polio during the same era, its appearance, along with typhus, was linked to increased immigration from Europe. The Public Health Council deemed encephalitis lethargica “a disease dangerous to the public health” and in need of further investigation.³² Locally, it had a fatality rate of from fifteen to forty percent, a figure based principally on cases severe enough to require hospitalization. Adults were more often victims than children, incidence was higher during the winter months, and no evidence was found to indicate that encephalitis lethargica was a contagious disease.

Some survivors appeared to recover completely after the first stage of encephalitis lethargica subsided. Others seemed to improve only to relapse or to develop complications with symptoms often markedly different from those characteristic of the early stages of the illness. These individuals suffered from chronic or secondary encephalitis lethargica. In children, the residual effects most frequently reported were behavioral disorders, while adults often exhibited a condition that was labeled postencephalitic Parkinsonism (PEP).³³ PEP could surface at any age, presenting rapidly increasing debilitating effects including rigidity but as a rule no tremors.

Cognitive impairment, psychological changes, memory loss, depression, and paralysis – these were the burdens carried by survivors of encephalitis lethargica. Their suffering might last for decades. Inexplicably, some victims experienced severe chronic complications that lingered for years and then recovered to lead a normal life. Such was the story of Marjorie “Daysey” Day, a gifted student who developed symptoms in 1926 while studying at Oxford and fell into a coma followed by years of bizarre behavior. Eventually, and with no apparent intervention, Daysey got well and resumed her life as a teacher and something of a free spirit.³⁴ She worked for many summers at the Rockport Lodge, a haven for Massachusetts factory girls, and lived to be nearly one hundred. Alice Cardillo was not so lucky.

ALICE’S LIFE BEFORE HER SICKNESS (1885–1926)

Like the woman who would later become a distant relative through marriage, Alice was born in 1885 (one year before Almena). Unlike Almena,



Stages of a Life

Top: Alice Cardillo (right) as a young woman (c. early 1900s).

Above: Alice Cardillo just prior to her illness (c. early 1920s).

she immigrated to the Boston area as a child from Italy, rather than as a married young woman from Nova Scotia. Alice's story begins in the hills of the Campania region of Italy, where she was born in the village of Sant'Angelo around 1885.³⁵ An earthquake in 1980 destroyed much of the community, including church records and other information about her family's origins. Her given name was Carmela DiNosse, the oldest child of Gabriel and Maria,

who emigrated when she was about three years old and settled in Boston's North End. There are few surviving details about Carmela's early life, other than that she had little schooling and was something of a tomboy. As a child, she won the neighborhood prize for her skill at marbles and jacks. Eventually, people began to call her Alice.

Two of her sisters disappeared from the census rolls and may have died at an early age. They were never discussed. Alice's father had studied for the priesthood in Italy before he left his calling to marry Maria, and he boasted that his ancestors were well educated — lawyers, doctors, and a judge among them. He claimed that the scourge of alcohol brought them all down. No one is sure how Gabriel earned a living when he moved to Boston. For a time, Maria worked in a potato factory, a job that ruined her lungs.

At some point during her young adulthood, Alice went to work for a tailor in downtown Boston. On her way to and from the shop, she caught the eye of the ambitious young proprietor of a shoeshine and hat-cleaning establishment on the corner of Court and Tremont Streets. He was Ciriaco "Jerry" Cardillo, also an Italian immigrant from the Campania region. The pair married in 1905 and, after a series of moves, settled in the Dorchester section of the city where they purchased a storied Victorian mansion, designed by architect Luther Briggs, that was beginning to show signs of age and neglect. There they raised their family and became fixtures in the neighborhood. Jerry started a number of businesses; not all did well. The most stable of his enterprises was a fruit store located on Broadway in South Boston. Between 1906, when their first child was born, and 1926, when she fell ill, Alice experienced at least twelve pregnancies. Eight children survived to adulthood. She was the center of their lives, and they all adored her, even those who were too little to remember her before she was stricken with the sleeping sickness.

Her children often described her as an engaging presence with a sense of humor and an outgoing personality. The exhausting work involved in running a large household that included her aging parents for several years did not break her spirit. She loved music, movies, and listening to the radio. She was renowned for both her generosity and her temper. Alice gave food away to needy neighbors when her own family had little to spare. She was a stickler about table manners, insisting that her children behave well or suffer the consequences. They passed on many stories, lovingly recounted, about committing transgressions and then being on the receiving end of a piece of fruit hurled with such force that it broke a window, or the jab of a fireplace poker, or a well-placed "pinch with a twist." Alice's vitality and her status as the center of the Cardillo household ended without warning, abruptly, and in heartbreaking fashion.

The Cardillo siblings recalled that after their mother gave birth to her eighth healthy child and fourth son, Arthur, in 1925, she was never herself again. She may have experienced the headache and flulike symptoms that marked the onset of encephalitis in other victims. Her children did not remember the exact details of the onset of her decline. They did recall, however, that where once she was lively and vibrant, their mother was now extremely fatigued all the time, and she could not stop sleeping. One researcher working in the 1940s found a correlation between major life stressors, particularly physical exhaustion and pregnancy, and the development of encephalitis lethargica.³⁶ Alice was forty years old when Arthur was born. After twenty years of childbearing and child rearing, she must indeed have been a tired woman.

ALICE'S STRUGGLE WITH ENCEPHALITIS LETHARGICA (1926–1944)

While Almena's illness is documented informally in her sister Emma's memoir, Alice's ordeal is remembered only through family stories, a series of faded photographs, and a few vital records. Alice's children all gave similar accounts of how she took to her bed soon after her last pregnancy and spiraled into total helplessness. Their anecdotes seemed to indicate a quick progression from vitality to invalidism.

Photographs add another dimension to the story. Almena Clayton's son Willie was something of an amateur photographer in the 1930s. Many years before, the Cardillo family had given him shelter following a break with his parents over his inability to hold down a job and contribute to the family's fragile finances. He became very fond of Alice, and he fell in love with her oldest daughter, Abbie. In the spring of 1931, Willie, Abbie, and her young brother Jerry visited Bosworth Hospital in Brookline, Massachusetts. Alice was a patient there. Willie took a series of photographs showing Alice in various poses looking purposefully into the camera. He captures her as she is seated peacefully on a bench with purse in hand, picnicking on a blanket on the grass with Abbie and Jerry, and, most tellingly, standing with her two arms raised in victory fashion. She is smiling for the camera as if to indicate her pleasure at being able to perform this simple exercise. In 1931, six years after Arthur's birth and the onset of symptoms, she was still mobile, although sick enough to be hospitalized by a family with few economic resources to bear the expense.

Bosworth Hospital was a private facility that operated in the first half of the twentieth century in what is now a private residence. Data concerning the type of patients it accepted when Alice Cardillo was a resident are hard

to come by. The 1930 U.S. Census lists it simply as a hospital in the town of Brookline. In 1940, Bosworth was overseen by Eliza Lindberg, who authorized the use of electroconvulsive therapy on at least one patient.³⁷ The Brookline Historical Preservation Commission has determined that in the 1950s, Bosworth was a private convalescent home directed by Elsie Oreon, a registered nurse and proponent of water and massage therapy.³⁸

Although the Cardillo siblings often spoke of their mother's illness, her personality changes, and her many years as an invalid, they never discussed her time at Bosworth Hospital. Family members today do not recall Abbie ever showing them the photographs that Willie took in 1931. Her nieces discovered them while going through some boxes of Abbie's personal effects after her death in 2005. Perhaps the silence was related to the stigma of her mother spending time in a mental hospital. Maybe it was just a painful episode in the family history that Abbie and her siblings chose to put behind them.

Eventually, Alice developed recognizable symptoms of PEP (postencephalitic Parkinsonism). She lost her strength, the use of her limbs, and even the ability to speak. She spent her days confined to bed, completely dependent on family members with whom she communicated mostly by blinking her eyes. The former ballroom of the old house was converted into a sickroom. There she stayed imprisoned in her rigid body until her death in 1944, nearly two decades after the birth of her last child and the first signs of encephalitis lethargica. It was a long and wrenching farewell.

TWO FAMILIES RESPOND

How a family reacts, adapts, and adjusts to the debilitating illness of one of its members is influenced by a number of factors, including the point in the family's life span at which the disruption occurs. A critical question involves how well individuals are able to discard their former roles and assume new ones necessitated by the family emergency. Sociologists Helen Mederer and Reuben Hill note that families "prize order and predictability" and ask under what circumstances they will "give up their scripted roles, rules and procedures to regroup around a different allocation of roles and duties."³⁹

The two families under examination here were at different points in their development when tragedy struck and were living in different historical eras. Consequently, their patterns of coping followed divergent paths. When Almena was taken ill in 1911, she was only twenty-seven years old and her family was quite young. Her husband, whose previous role had been principally breadwinner, suddenly was thrust into the position of nurse and

homemaker as well. He was called upon to construct medical equipment to accommodate Almena's rigid limb, to perform household tasks such as laundry and cleaning, and to provide child care. As might be expected, he was exhausted by these added responsibilities and by concerns about both his wife's recovery and the mounting medical bills.

While Almena remained at home in the first stages of her illness, Richard received help from his sisters-in-law, particularly Emma who lived not far away, and from neighbors who provided support. When Almena was admitted to the hospital, he was forced to engage a housekeeper, an additional economic burden. Eventually, when Almena was discharged and taken in by relatives in Nova Scotia, her immediate family was broken up. Richard returned to his job in Newton, while the children remained with their mother and extended family in Canada.

While disruptive to the nuclear structure of the Clayton family, the painful separation brought about the desired results. Within a few months, Almena began to walk with the aid of crutches. When she recovered her strength, she was able to participate in a pilgrimage to the Shrine of Saint-Anne-de-Beaupré in Quebec. There she ran into a childhood friend, and, in the excitement of the reunion, took her arm and walked without her crutches. The family always credited the joyous event to divine intervention. Whatever the reason, Almena thereafter learned to walk with a cane and returned home nearly a year after her departure. Although her mobility would be compromised somewhat for the rest of her life, she was able to resume her former roles as wife, mother, and homemaker. Almena experienced two pregnancies following her return, one that resulted in a stillbirth and the other in a healthy daughter. She later rejoined the workforce as a factory operative, thus contributing to the family's finances for a number of years.

When Alice became ill in 1926, she was in her early forties. Her family as a unit was at a much later stage than Almena's had been under similar circumstances. She had been married for over twenty years. Her oldest children were young adults, and they would be the ones to assume the caregiving responsibilities. As a result, their story runs counterpoint to that of the Claytons, where adult family members temporarily altered their familiar lifestyles to care for the children and nurse Almena back to health. British researchers Jo Aldridge and Saul Becker, who investigated the outcomes when parents become so sick that they must depend on their children, point out that "educational, social and emotional experiences and health can [of the children] often be seriously jeopardized."⁴⁰ At the same time, they note that caring for others can have a beneficial impact on children and the larger society, and it can be a positive factor in their development. Both sets of



Alice Cardillo As a Bosworth Patient

This photo shows Alice Cardillo during her time at Bosworth Hospital in Brookline, MA, 1931.

consequences played out among the Cardillo children, who sacrificed for the good of their mother for a very long time.

The older siblings were in their teens when Alice Cardillo first became ill, and, as she grew progressively more helpless, they became deeply involved in her care. Jerry, their father, seems not to have taken an active role, despite the fact that earlier in the marriage he had helped out with the housework and child rearing. Perhaps in denial, he became increasingly wrapped up in his business interests and formed emotional attachments outside the family circle. Work roles among the young adult and adolescent children were allocated along traditional lines. The daughters provided the nursing care, while the sons performed the more arduous chores such as carrying their mother to the bathroom and lifting her when she had to be moved any distance.

The fifth child, Jennie, left high school after her first year to devote her time to running the household, nursing her mother, and helping to raise the two little boys. Arguably, Jennie sacrificed the most, but she also benefited from her position as the principal caregiver. She was deeply loved and admired



Richard and Almena Clayton in Their Later Years (c. 1940s)

by her grateful brothers and sisters, but in a sad twist, Jennie, the substitute mother, married late and had no children of her own. Of the eight siblings, only the youngest daughter finished high school.

It was the era of Prohibition, and two of the older Cardillo brothers became involved in the bootleg business in part to help out with the family's mounting bills, including, in all probability, the cost of Alice's treatment at a private psychiatric facility. They spoke of being drawn into the illegal venture because of economic hardship, mentioning medical expenses only vaguely. Most families of their socioeconomic status would in all likelihood have placed a parent exhibiting signs of mental illness in a state hospital.⁴¹

Perhaps it was family pride or, as members of a first-generation immigrant community, distrust of government agencies that motivated the Cardillos

to choose an alternative that placed them in difficult economic straits. As author Stephen Puleo points out in his history of the Italian community in Boston, when local politicians, even those from within the ethnic group, offered assistance during the hardship years of the Great Depression: “a large majority of Boston Italians did not seek government relief,” preferring instead to take care of their own.⁴²

Despite the many negative aspects of growing up in a household where a previously capable and beloved parent became disabled, the Cardillo family exhibited remarkable resilience in the face of the protracted crisis. In analyzing the concept of family resilience when under duress, researcher Joan Patterson found that while a disruption can lead to “a discontinuity in the family’s trajectory of functioning,” it can also result in positive outcomes.⁴³ When family members believe they can meet the challenges fate has dealt them, they may “develop a shared identity,” and the chores that some might find burdensome become routine and even ritualistic as they give rise to “a sense of who a family is and how they are different from other families.”⁴⁴ Psychologist Diane Marsh suggests that family resilience does not emerge in spite of a major crisis, but because of it. Consequently, “resilient families reconstruct themselves in adaptive ways.”⁴⁵

As the Cardillo children moved from being dependents to becoming nurturers, they exhibited a number of the characteristics that Marsh identifies in resilient families. They developed routines and learned practical skills — how to cook and keep house. They practiced exemplary nursing techniques; the family doctor marveled at the fact that although almost entirely confined to her bed, Alice never developed a bedsore. Despite the difficulty involved, her children took turns regularly shifting her position. They kept their mother informed as to the whereabouts of the two youngest boys, for Alice never lost her interest in their well-being. She could not rest until she was sure that they were safely home in their beds at night. The older children did their best to keep their mother entertained, playing the radio for her so that she could follow the fortunes of her favorite soap opera characters. Her son-in-law, Willie, sometimes set up a projector in the sickroom to show home movies that helped Alice pass the endless hours she spent in place. Her children learned to find humor in the everyday as they threw parties, entertained relatives and friends, and determined to lead normal lives.

Although all was not harmonious, particularly between the two oldest sons, who often had their differences, the Cardillo family bonds, strong initially, grew even more so during the long years of their mother’s illness and continued throughout their lives. Their sense of themselves as a family with a

special mission to protect and care for their mother was an overarching theme in the many stories they passed on to their offspring, nieces, and nephews.

ASSESSING OUTCOMES

The relationship between the Cardillo and Clayton families that was forged through two marriages began when son Willie Clayton left home and moved in with the Cardillos. After he and Abbie married, he became an integral part of the support system that nurtured Alice during the many years of her deteriorating health. Willie's own mother, Almena, had recovered from her physical ordeal, yet their family dynamic was more troubled than the one he observed emerge among the Cardillos.

Almena at midlife could be difficult and at times unforgiving. She and Richard bickered constantly, perhaps the result of resentment on his part over the sacrifices he had made during her illness and on her part for having to work outside the home to keep the family from sinking into debt. They both had a fractured relationship with their middle daughter, who had been a toddler when the family was uprooted during Almena's recuperation. A chronic runaway during her teen years, she fell in with a tough crowd, and eventually her frustrated parents took her to court and agreed to have her placed in a school for "wayward girls" in Lancaster, Massachusetts.⁴⁶ When her time there was over, she did not go home but moved on to New York City. Almena fought bitterly with her youngest daughter over her romance with Alice's eldest son, who was thirteen years her senior and of whom Almena deeply disapproved. Eventually, the pair married against Almena's wishes. In spite of these and other challenges, the Claytons managed to avoid permanent rifts and to develop positive familial relationships, particularly as they grew older and the children found their footing.

Almena's story, for all its dysfunctional aspects, illustrates a number of affirming themes, most notably those related to personal resilience. Mental health specialists have identified a variety of factors and strategies for understanding and building individual resilience, which may be defined as "adapting well in the face of adversity . . . such as family and relationship problems, serious health problems or workplace and financial stressors."⁴⁷ Certainly Almena experienced all of these, the most defining being her yearlong bout with polio. Clinicians suggest such proactive measures as carrying out decisive actions, taking care of oneself, and building relationships as ways to survive the rough patches in one's life.

When Almena's health was in peril, she agreed to move back to Nova Scotia for an extended period, and when her family's financial stability was precarious, she took the resolute step of reentering the workforce. Factory work could not have been easy given her compromised mobility. She ultimately repaired broken

relationships with her daughters, son, and son-in-law and developed a warm friendship with her daughter-in-law Abbie. An old photo shows her seated somewhat awkwardly in her grandson's baby carriage smiling down at Abbie and her sisters and at her own daughter Edna at a picnic on the grass. In another, taken in her later years, she is walking in the woods with one of her sisters, using a stick for support. Both photographs illustrate Almena's determination to participate in family events that must have been difficult for her physically due to her disability.

A number of the Clayton family photographs showcase Almena's attention to her appearance, a tangible indication of her resolve to maintain her dignity and self-respect even as she grew older. She took pride in dressing fashionably, if not expensively, and frequently treated herself to a manicure at the end of an exhausting week at the factory. She entertained her friends regularly and remained active well into her senior years, even hosting a gala seventy-fifth birthday party for her sister Josephine. Almena developed ovarian cancer shortly after Richard's sudden death in 1949 due to injuries sustained in a fall from an unsteady ladder while working as a custodian in a Dorchester settlement house. She passed away the following year at age sixty-five.

Alice Cardillo's death also was preceded by a family tragedy. In 1943, her youngest child Arthur, the darling of all the older siblings who helped raise him, enlisted in the army for service in World War II, as did many of his friends and neighbors. He was dispatched to Fort Bliss in Texas for his basic training. Arthur wrote letters home regularly, and Alice's daughters dutifully read them all to her. She could signify her understanding only by blinking. In February of 1944, Arthur was accidentally shot in the chest by his roommate while on maneuvers in New Mexico and died the following day. He was just eighteen years old.

The heartbroken Cardillo siblings tried their best to hide the truth from their mother, holding the wake in her son Andy's home and reading fabricated letters to her as they feigned cheerfulness and struggled to mask their own grief. They always suspected that she guessed the truth, for Alice lost her own long battle a scant two and a half months later in 1944. The cause on her death certificate reads as follows: "MYOCARDITIS 1 YR ENCEPHALITIS LETHARGICA 18 YRS." She was laid to rest next to Arthur at Mount Auburn Cemetery in Cambridge. Alice was fifty-nine years old.

Encephalitis lethargica, save for the work of Oliver Sacks and a small number of medical researchers and those personally touched by its awful grip, has largely faded from public consciousness. In wrapping up his story of the influenza pandemic of 1918, author John Barry observes of encephalitis lethargica that:

although no pathogen was ever identified and the disease itself has since disappeared — indeed, there is no incontrovertible evidence

that the disease, in a clearly definable scientific sense, ever existed — physicians at the time did believe in the disease, and a consensus considered it a result of influenza.⁴⁸

Such observations are evidence of its history in large part as a reference point in the saga of the far more consequential great influenza. Polio, on the other hand, still lives on in the memories of millions of Americans who were children during the panics of the nineteen fifties and in the biographies and films about the president who was one of its victims. In 1952 alone, records indicate more than fifty-seven thousand cases in the United States, resulting in lifelong paralysis for many and death for three thousand.⁴⁹ Although no longer a threat in the Americas, polio still manifests itself from time to time in Asia and Africa.⁵⁰

Members of the general public have commonly assumed that President Roosevelt's ordeal with polio led him to empathize with other victims, not only those of the disease that attacked him, but also those struggling with poverty, discrimination, and hardship in general. His measures to restore an economy in the grip of the depression of the 1930s gave rise to social welfare measures that can be linked to a safety net for families in crisis today that the Cardillos and Claytons did not have available to them. Visiting nurses, physical therapy, personal care assistance, and hospice are services now routinely offered to individuals with acute and chronic medical conditions, and, depending on age, income, and location, partially subsidized by the government.

Taking advantage of these and other lifelines has become routine and, as such, not a sign of weakness or family dysfunction. In earlier times, families relied principally on themselves as the stories of Almena and Alice illustrate. The strategies their caregivers fashioned to manage their challenging situations and the emergent themes of family reliance and resilience provide a small but not insignificant glimpse into the social history of the working class in Massachusetts in the early years of the twentieth century.

HJM

Notes

1. James V.W. Boyd, "A Study of an Epidemic of Infantile Paralysis (Acute Epidemic Poliomyelitis) Occurring in the Southern Connecticut Valley District During the Year 1912" (Nov. 1, 1911, to Nov. 1, 1912), 119–142. The study is in Massachusetts State Board of Health, *Infantile Paralysis in Massachusetts, 1907–1912: Together with Reports of Special Investigations in 1913, Bearing upon the Etiology of the Disease and the Method of Its Transmission* (N.p.: n.p., 1914). Reproduction, Ulan Press, 2011.

2. Anita Danker and Marie Campo, *Growing Up Cardillo: A Family History*, (unpublished manuscript, 2014). This family history is based on informal interviews with family members and neighbors, vital records, documents, notes, letters, photographs, and stories passed on orally from one generation to the next. The history is the work of two of Alice Cardillo's granddaughters who sought to preserve their heritage after the death of their parents and all of their uncles and aunts and their respective spouses. The authors exchanged information between 2010 and 2014 with their surviving cousins, children of the Cardillo siblings, and maintain copies of their resource materials and memorabilia in their private collections.
3. Hamilton I. McCubbin, Marvin B. Sussman, and Joan M. Patterson, eds. *Social Stress and the Family: Advances and Developments in Family Stress Theory and Research* (New York: Haworth Press, 1983). This collection of research essays examines various situations causing family stress and how members and individuals cope.
4. Joan M. Pattinson[Patterson?], "Integrating Family Resilience and Family Stress Theory," *Journal of Marriage and Family* 64 May (2002): 349–360.
5. Jo Aldridge and Saul Becker, "Children as Carers: The Impact of Parental Illness and Disability on Children's Caring Roles," *Journal of Family Therapy* 21 (1999): 303–320.
6. Diane T. Marsh, *Family Resilience: Surviving and Thriving* (Harrisburg, PA: Office of Mental Health and Substance Abuse Services, 2008).
7. Naomi Rogers, *Dirt and Disease: Polio before FDR* (New Brunswick, NJ: Rutgers University Press, 1996). While focusing on the 1916 epidemic in New York City, this study is comprehensive in its description of the emergence of the germ theory, the attempts of the medical scientific community to understand and tame the disease, the role of public health agencies in trying to contain the epidemic, and the irony of blaming the immigrant community and its perceived nonhygienic lifestyle, while the obsession with cleanliness among the middle class made it more vulnerable to the ravages of polio.
8. David M. Oshinsky, *Polio: An American Story* (New York: Oxford University Press, 2005), 11.
9. James Warren Sever, "Anterior Poliomyelitis: A Review of the Recent Literature in Regard to the Epidemiology, Etiology, Modes of Transmission, Bacteriology and Pathology," in Massachusetts State Board of Health, *Infantile Paralysis in Massachusetts*, 1. In *Dirt and Disease*, Rogers writes at length about the tendency of public health officials during New York's 1916 epidemic to blame the outbreak on the city's large immigrant population despite evidence to the contrary.
10. Mark W. Richardson, "The Occurrence of Infantile Paralysis in Massachusetts, 1907–1912," in Massachusetts State Board of Health, *Infantile Paralysis in Massachusetts*, 48.
11. According to the U.S. Centers for Disease Control and Prevention, polio is a virus that thrives in the throat and intestines and is spread through person-to-person contact with the feces or, less frequently, with the fluid from the coughs or sneezes of an infected individual. "What is Polio," U.S. Centers for Disease Control and Prevention, accessed March 12, 2015, www.cdc.gov/polio/about/.

12. Herbert C. Emerson, “An Epidemic of Infantile Paralysis in Western Massachusetts in 1908,” *Boston Medical and Surgical Journal* (July 22, 1909).
13. Oshinsky, *Polio*, 11. The majority of victims in early epidemics in the United States as well as in later epidemics were male.
14. Daniel J. Wilson, *Living with Polio: The Epidemic and Its Survivors* (Chicago: University of Chicago Press, 2005), 67–100.
15. Robert W. Lovett, “Principles of the Treatment of Infantile Paralysis,” in Massachusetts State Board of Health, *Infantile Paralysis in Massachusetts*, 143.
16. Lovett, “Principles,” in *Infantile Paralysis in Massachusetts*, 149.
17. John M. Barry, *The Great Influenza: The Story of the Deadliest Pandemic in History* (New York: Penguin, 2005), 6.
18. *Ibid.*, 35.
19. Emma Sampson, *Out of the Dark: The Autobiography of a Cured Cancer Patient*, (unpublished manuscript, n.d.), 6. Almena’s twin sister, Emma Sampson, was a multitasking individual who raised a family of five on her own after the death of her husband, invented an improved colostomy bag system after her surgery for colon cancer, cared for others who survived similar ordeals, built her own home in Freehold, New Jersey, and was a prolific writer despite a limited education. Her memoir documents and describes the story not only of her own life but also of the history of her family’s roots in Nova Scotia.
20. Lyman Walkins, MD, “Neuritis, Rheumatism, and Sciatica,” in *The Eclectic Medical Journal*, ed. John K. Scudder, vol. 66 (Cincinnati, OH: Scudder Brothers Company, 1906), 174.
21. Details about Almena Clayton’s illness were described in vivid detail in her sister Emma’s memoir, *Out of the Dark*. She was an eyewitness and participated in Almena’s care before she was moved to Nova Scotia for recuperation.
22. “About Newton-Wellesley Hospital: History and Milestones,” accessed April 13, 2013, <http://www.nwh.org>.
23. Sampson, *Out of the Dark*, 315. For a nostalgic look at the once popular social known as the whist party, see William Pepe, “Bring Back the Whist Party,” *South Shore Senior News*, February 27, 2014, accessed September 28, 2015, <http://www.southshoresenior.com>.
24. Joel A. Vilensky and Sid Gilman, “Encephalitis Lethargica during the Epidemic Period,” in *Encephalitis Lethargica During and After the Epidemic*, ed. Joel A. Vilensky (New York: Oxford University Press, 2011), 8–38.
25. Oliver Sacks, *Awakenings* (New York: Vintage, 1999).
26. Joel A. Vilensky, Roger C. Duvoisin, and Sid Gilman, “Oliver Sacks, Awakenings, and Postencephalitic Parkinsonism,” in *Encephalitis Lethargica*, 205.
27. Von Economo’s groundbreaking work on encephalitis lethargica is frequently cited in sources covering the topic. One recent work with a chapter devoted to the researcher is Molly Caldwell Crosby, *Asleep: The Forgotten Epidemic that Remains One of Medicine’s Greatest Mysteries* (New York: Berkley Books, 2010), 13–20.

28. Association for Research in Nervous and Mental Disease, *Acute Epidemic Encephalitis (Lethargic Encephalitis): An Investigation by the Association for Research in Nervous and Mental Disease*, (New York: Paul B. Hoeber, 1921).
29. Vilensky and Gilman, "Encephalitis Lethargica," in *Encephalitis Lethargica*, 26.
30. Massachusetts Department of Public Health, "Open-Air Schools," *The Commonwealth* (January–February, 1921) accessed June 20, 2015, <http://books.google.com>.
31. Massachusetts Department of Public Health, "Open-Air Schools," 54.
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33. Ruth Levy Guyer, *A Life Interrupted: The Long Night of Marjorie Day* (Author, 2012).
34. Danker and Campo, *Growing Up Cardillo*, 12–15, 56–58.
35. Vilensky and Gilman, "Secondary Encephalitis," 167.
36. Edward Shorter and David Healy, *Shock Therapy: A History of Electroconvulsive Treatment in Mental Illness* (Piscataway, NJ: Rutgers University Press, 2007), 76.
37. "Here and There," *The Posse Gymnasium Journal* 19 (1911):11, accessed May 5, 2015, <https://books.googlebooks.com>.
38. Helen Mederer and Reuben Hill, "Critical Transitions Over the Life Span: Theory and Research," in *Social Stress*, 39–40.
39. Aldridge and Becker, "Children as Carers," 303.
40. Massachusetts Department of Mental Health (administrator) in discussion with the author, June 2015.
41. Stephen Puleo, *The Boston Italians: A Story of Pride, Perseverance, and Paesani, From the Years of the Great Immigration to the Present Day* (Boston: Beacon Press, 2007), 178.
42. Pattinson, "Integrating Family Resilience," 351.
43. *Ibid.*, 358.
44. Marsh, *Family Resilience*, 4.
45. National Park Service, "Places Where Women Made History: Lancaster Industrial School for Girls," accessed June 8, 2015, www.nps.gov. Recognized as a progressive institution dedicated to the humane treatment and rehabilitation of troubled young girls, the Lancaster Industrial School for Girls was founded in 1854 and continued in operation until 1975. It is now a minimum security prison and prerelease center.
46. American Psychological Association, "The Road to Resilience," accessed May 25, 2015, <http://www.apa.org/helpcenter/road-resilience.aspx>. This article, posted on the APA Help Center website to aid individuals coping with life-altering challenges, is the work of a number of contributors from the field of mental health.
47. Barry, *Influenza*, 392.
48. Oshinsky, *Polio*, 161.
49. Julie Silver and Daniel Wilson, *Polio Voices: An Oral History from the American Polio Epidemics and Worldwide Eradication Efforts* (Westport, CT: Praeger Publishers,

2007), 141–155. Polio continues to be a concern to medical researchers, and the World Health Organization, supported by Rotary International and the Gates Foundation, is committed to its eventual eradication throughout the world.

THE NEW YORK TIMES, WEDNESDAY, JANUARY 14, 1920.

**NEW SLEEPING DISEASE
MYSTIFIES LONDONERS**

*Patients Drowsy When Aroused,
but Are Otherwise Normal—
Malady Not Infectious.*

Copyright, 1920, by The New York Times Company.
Special Cable to THE NEW YORK TIMES.

LONDON, Jan. 13.—Doctors have a new disease, encephalitis lethargica, to puzzle over. Several cases are now under treatment in the London Hospital. The chief symptom is sleepiness, yet the disease has nothing in common with the deadly "sleeping sickness" of Africa. In talking about the cases today an official of the London Hospital said:

"The patients are very difficult to awaken, and when aroused are likely to remain in an abnormally drowsy condition. Their state is perhaps best described by the word 'muzzy.' They seem very heavily dazed. In other respects they appear fairly normal, and it is this absence of a number of attendant symptoms that makes the disease more puzzling.

"The greatest interest is being taken in the outbreak, and an authoritative medical committee of experts has been set up to discover its origin and cure. So far as is known, no women have been attacked, and the patients are all Londoners, not seafaring men. Encephalitis lethargica is not in the least infectious. That in itself proves it is not 'sleeping sickness.' Frankly, we are mystified."

Afterword

The Ravages of Encephalitis Lethargica

Encephalitis lethargica spread throughout the world slowly beginning about 1917, its seriousness becoming apparent to the medical community just as the world was reeling from the crises of World War I and the 1918 influenza epidemic. The medical profession scrambled to determine the origin of this epidemic encephalitis and find its cure. Municipal health departments worked to warn the population in hopes of preventing further outbreaks.

The March 11, 1923, *New York Times* ran the headline “SLEEPING SICKNESS WARNING SENT OUT.” It reported, “In an effort to prevent an increase in the number of cases of encephalitis lethargica, commonly known as ‘sleeping sickness,’ and other respiratory diseases. Dr. Frank J. Monaghan, Health Commissioner, issued a warning yesterday against careless coughing, sneezing and spitting.”

By 1927, doctors still had few answers about this disease, yet the “Sleepy Sickness” epidemic was coming to an end. In her book, *Asleep: The Forgotten Epidemic that Remains One of Medicine’s Greatest Mysteries*, Molly Caldwell Crosby, writes:

This epidemic would strike as many as 5 million people throughout the world, killing a third of them and leaving thousands more institutionalized for the rest of their lives. The victims fell into a long sleep—for weeks or even months. Many never awoke. But the world soon learned that dying was not the tragedy of this disease; surviving it was.¹

Crosby writes that physicians’ estimates indicate that a third of victims of this disease died from it, a third recovered, and another third developed permanent disabilities.

1. Molly Caldwell, *Asleep: The Forgotten Epidemic that Remains One of Medicine’s Greatest Mysteries* (New York: Penguin Press, 2010.) Oliver Sacks, author of *Awakenings*, writes: “Molly Crosby has provided a brilliant and deeply moving account of the fearful years between 1915 and 1927, when this mysterious, worldwide pandemic struck, giving us vivid, intensely human portraits.”