



Maureen Stefanides at New York-Presbyterian Hospital with her father, Joseph Andrey, waiting to move to a nursing home despite their efforts to arrange for 24-hour care at his apartment.

Credit Victor J. Blue for The New York Times

Fighting to Honor a Father's Last Wish: To Die at Home

By **NINA BERNSTEIN** SEPT. 25, 2014

Joseph Andrey was 5 years old in 1927 when his impoverished mother sold him to the manager of a popular vaudeville act. He was 91 last year when he told the story again, propped in a wheelchair in the rehabilitation unit of a nursing home where it seemed as though age and infirmity had put a different kind of price on his head.

Craning his neck, he sought the eyes of his daughter, Maureen Stefanides, who had promised to get him out of this place. “I want to go home, to my books and my music,” he said, his voice whispery but intense.

He was still her handsome father, the song-and-dance man of her childhood, with a full head of wavy hair and blue eyes that lit up when he talked. But he was gaunt now, warped like a weathered plank, perhaps by late effects of an old stroke, certainly by muscle atrophy and bad circulation in his legs.

Now she was determined to fulfill her father's dearest wish, the wish so common among frail, elderly people: to die at home.

But it seemed as if all the forces of the health care system were against her

— hospitals, nursing homes, home health agencies, insurance companies, and the shifting crosscurrents of public health care spending.

Her father had been discharged by a hospital to a nursing home like this one, supposedly for rehabilitation, so many times that even she had lost count. The stays, long or short, had only left him weaker, harder to care for at home with a shrinking allotment of help from aides and more prone to the infections that sent him back to the hospital.

This time she had fiercely opposed his being discharged to anywhere but home, a small walk-up apartment in Manhattan that her parents shared for half a century before her mother's death. Yet over her protests and his own, he had been transferred here anyway, to Jewish Home Lifecare in Morningside Heights, a sprawling institution an hour from where she lived. Later, he would ask, "Are you sure you didn't put me here?"

"No matter what I do, they want you in a nursing home," Ms. Stefanides told him, promising the placement would be temporary. "I think they're making money off you."

Records would show that her father's case let the nursing home collect \$682.48 a day from Medicare, about five times the cost of a day of home care.

By now Ms. Stefanides was a veteran of battles with the health care system, but it still baffled her. A public-school teacher, she could not afford out-of-pocket home care, and though her father qualified for both Medicaid and Medicare, the flow of money seemed to bypass what he actually wanted at the end of life.

Home care agencies abruptly dropped or refused high-needs cases like her father's as unprofitable under changes in the state's Medicaid program. Hospitals, eager to clear beds, increasingly sent patients to nursing homes. The nursing homes were often too short-staffed to reliably change diapers but still drew premium Medicare rates, ordering hours of physical therapy and other

treatment that studies showed was often useless or harmful.

Even hospice was limited. Now mostly for-profit, hospice companies would provide supervision and visits at home a few times a week through Medicare if a doctor certified that Mr. Andrey had only six months to live. The hidden catch: He would lose all Medicaid home care, the daily help he needed to be home at all.

Ms. Stefanides smoothed her father's hair and touched his cheek, preparing him for her exit.

At 54, she was still slim as a girl and fragile-looking. For most of the past year, she had lifted and rolled and washed her father by herself after the home care aide's eight-hour shift ended. She would rush to her father's place from the East Harlem school where she taught fifth grade, feed him supper and get him in pajamas, leave him sleeping under a neighbor's eye, and then head home, 35 blocks away, to her waiting husband and the dogs she rescued from animal shelters.

She was prepared to do as much again, but she could not quit her job. And now the home care agency had refused to reinstate her father's aide services.

"He's in and out of the hospital too much," an office manager for the agency said when she demanded an explanation. "This is not allowing our girls to make any money."

Her father was a World War II veteran who had paid taxes all his life, working the night shift in the Murray Hill post office. She was his health care proxy and had power of attorney. But what good was all that?

"It's a terrible situation they've put us in," Ms. Stefanides said in an agitated phone message left on this reporter's voice mail. "My father wants to die at home, he knows he's dying. And here I am proving I'm power of attorney, that I'm guardian, and it means nothing, it falls on deaf ears."

Her recorded voice continued, rising in anger and resolve as she rushed to explain her father's straits before being cut off in midsentence.

The message was left at 4:46 p.m. on May 23, 2013, the day after he was taken by ambulance to his fourth or fifth nursing home stint in two years. She would have eight months and eight days to fight for her father before he died.

Dying in America

While Joseph Andrey's daughter battled the health care system, a national panel appointed by the federally funded Institute of Medicine was preparing a sweeping critique of how the system handles just such cases. The report, "Dying in America," released last week, calls for a fundamental overhaul of the country's end-of-life care.

For most people, death does not come suddenly, the report points out. With 48 times as many people reaching 85 than a century ago, and triple the number who turn 65, the likely course of death is long and unpredictable. In the new demographic reality, the immediate family is older, too, often literally unable to do the heavy lifting for the long haul.

Yet the system was never engineered to support families through this, and its financial incentives reward harmful transitions among homes, hospitals and nursing homes, said Dr. Joan M. Teno, a gerontologist and one of the report's authors.

"We have these frail older people moving about in the medical-industrial complex that we've constructed," Dr. Teno said. "It's all about profit margins. It's not about caring for people."

Many geriatric experts say that if the wasteful medical spending on this stage of life could be redirected, it could pay for all the social supports and services actually needed by today's fragile elders and their families. Instead, public money has been shuffled in the same system, benefiting health care

businesses but not necessarily patients.

A prime example is the abuse of short-term rehabilitation in nursing homes, improper charges that cost the public more than \$1.5 billion a year, federal inspectors for the Department of Health and Human Services reported in 2012. Medicare will pay premium rates for up to 100 days of services in a nursing home to rehabilitate patients. While such efforts can be beneficial, government investigations and lawsuits document a pattern of excessive or fraudulent orders for such services, often just before death.

As for dying at home, “you can’t believe the forces of the system that are arrayed against it,” said Jack Resnick, once a health system executive and now a doctor with a geriatric house-call practice on Roosevelt Island. “The way the reimbursement system works, these decisions are not made on the basis of what the individuals need. They’re based on what the institutions need.”

A nursing home is frequently the only place to find coverage for 24-hour care. But the care itself often falls short. In an analysis this year, federal inspectors found one in three Medicare patients who went to a nursing home from a hospital suffered harm, including preventable infections and medication errors.

Other national research confirms that pressure sores, falls and malnutrition are endemic in many nursing homes, and strongly linked to inadequate staffing. A 1987 law required enough staff to prevent such harms, but states’ enforcement has been weak in the face of a hugely profitable, politically powerful nursing home industry.

To Dr. Joanne Lynn, a veteran hospice physician consulted for the Institute of Medicine report, the problem goes beyond perverse financial incentives. Most developed countries spend much less on medical care over all than the United States, but nearly twice as much on social supports.

“Why can I get a \$100,000 drug but I can’t get supper?” she asked,

pointing to the budget sequestration that slashed federal spending on meals for seniors last year.

In the end, only a humane case-by-case approach can provide the right care for the last chapter of a long life like Joseph Andrey's, added Dr. Lynn, who directs the Center for Elder Care and Advanced Illness at the Altarum Institute, a research organization based in Ann Arbor, Mich.

"You have to get to know the real situation, what this person really needs to live comfortably and to have some meaning in their lives," she said. "They are more than just bodies with heart beats."

Poor Childhood, Rich Marriage

Mr. Andrey was the oldest child in a family so poor they begged in the street. His mother appealed to one of New York's newspapers. "Wants Her Sons Adopted," the front-page headline said on Aug. 7, 1927, above a family photograph "taken before domestic dissension set in."

In the picture, little Joseph stands solemnly with a younger brother before their father, a Greek immigrant. His Irish Catholic mother holds a baby on her lap. "As a result of her husband's failure to support her and the children," the caption says, she had decided "to seek a good home with a prosperous family for the two older boys."

The publicity drew the show business agent for the Loomis Twins, singing sisters looking for a sidekick. Money changed hands. And just like that, 5-year-old Joseph went from hunger in the tenements to room service at the Waldorf-Astoria and beyond, to the dining cars of trains speeding to vaudeville stages around the country.

"It was the best thing that happened in my life," he rasped from his wheelchair last year, recalling the highlight of his childhood: Dancing the leading toy soldier in a Christmas show at Radio City Music Hall.

Just as abruptly, at age 7, the idyll ended. His mother demanded him back, or else more money. He was returned to finish out a ragged childhood. To support the family, he left school at 14 for menial jobs, always longing to get back to the stage.

The draft took him instead to the Pacific theater in World War II. It was the ultimate escape from his parents' squalid fights, as he told it. Still in uniform, he met Florence Agnew, his future wife, at New York's Roseland Ballroom.

"They danced together all the time," their daughter remembered. "They danced around the house, for no reason at all. And then he danced with me."

Just for fun, all three would pile into a photo booth at Woolworth's, her father cracking them up with his Mighty Mouse voice when the shutter lights flashed.

By then he was sorting mail all night and working in hotel security on the side. He regretfully gave up his Broadway dreams. But he had achieved another fervent childhood goal: a happy marriage.

"It was like a dream," his son-in-law, Dean Stefanides, would say later, recalling how the couple laughed at their own infirmities.

The medical histories repeated again and again in hospital records were not such a big deal. Yes, she had an early hysterectomy, and in his 50s, he lost the tip of his penis to a cancer that never recurred. Yes, he had a stroke before 70; he seemed to recover completely, though five years later he would have to take medication daily to control seizures, and by 80, began having trouble with his legs.

But for years love and humor seemed to trump the toll of aging. Unable to extract each other from a cab one day, they told a funny story about it. Hard of hearing, they made fractured conversation another comedy routine.

Then Alzheimer's changed everything. At the couple's 50th wedding anniversary party, two weeks after the Sept. 11 attacks, relatives drew Ms. Stefanides aside: "Something is wrong with your mom." She had been calling a cousin from her apartment at 3 a.m., saying she wanted to go home.

She was 80. Her steep decline would last eight years.

Like many of the 15 million Americans caring for a relative with Alzheimer's, Ms. Stefanides and her father learned that Medicare does not cover long term day-to-day help, in any setting. They would have to turn to Medicaid, the shared state and federal program for poor and disabled people.

They were lucky. Under New York's unusually expansive version of Medicaid, a home attendant went daily to their fourth-floor walk-up in the Yorkville neighborhood to provide eight hours of unskilled "personal care assistance." Eventually, it was not enough.

The calls from her father would start at 5 a.m.: "I'm scared. What is it with your mother?"

She sometimes brought her mother to her place so her father could sleep, but that put new strains on her marriage.

She and her husband, an art director, had bought their duplex near Beekman Place in the early 1990s, before the advertising industry imploded. Now the apartment doubled as his freelance work space.

One day in 2007, her father broke down. Florence was banging on other tenants' doors, seeking her childhood room.

"I can't take it anymore," he said. "I can't run after her. Is there like a really nice place where we can put her?"

No. But there was DeWitt Rehabilitation and Nursing Center, a for-profit nursing home on East 79th Street.

“I was so ignorant of what nursing homes are,” Ms. Stefanides would say later. “My mother kept holding on to my sleeve, saying, ‘Take me out of here.’”

One day the nightgown slipped off her emaciated shoulders, revealing a mass of bruises. The woman in the next bed confided that Ms. Andrey, then wordless, had been beaten by an aide when she resisted some daily routine.

“The roommate told me that she cried under the covers when she heard my mother’s screams,” Ms. Stefanides recalled.

Now, the nursing home declines to discuss the case. At the time, her own complaints to the administration, the State Health Department and the police went nowhere. Fruitlessly, she hunted for a better place until her mother died.

‘Where’s My Dad?’

Mr. Andrey’s health worsened after he was widowed in 2009. But the less he could walk, the more he loved being home after brief hospital stays, nested with his Nat King Cole albums, cared for by live-in aides through Medicaid.

Ms. Stefanides was not prepared for the abrupt end of that way of life. Her father was in Lenox Hill Hospital for a urinary tract infection in spring 2011 when a discharge worker called her at school: He would not be sent home, because his home health agency, Excellent, had ended his services, and no one was there to care for him. Instead, he was to go to a nursing home for rehabilitation.

“Absolutely not,” Ms. Stefanides declared, rushing over. His hospital bed was empty. “Where’s my dad?” she cried.

He had been whisked to Kateri Residence, a Catholic nursing home on West 87th Street. And for more than a year, as his legs atrophied and he begged to go home, she was unable to get him out: No home health agency would take him.

Agencies like Excellent no longer wanted high-hours home care cases like her father's, explained Jack Halpern, the chief executive of MyElderAdvocate.com, when she briefly hired him to try to get her father home. Such cases were no longer lucrative.

She came to realize that it was the start of a larger upheaval. The administration of Gov. Andrew M. Cuomo was shifting billions in public spending on long-term care to private managed-care companies, which were paid a flat Medicaid rate for each enrollee. Key players were shunning fragile clients like her father in favor of seniors robust enough to bike to a social adult day care center for table tennis.

"They don't want heavy-care people, so they're denying them services," Mr. Halpern said later. "Everyone's getting shoved into nursing homes."

The nursing home, Kateri (which has since been sold and renamed), had financial incentives to keep Mr. Andrey: For up to 100 days, Medicare would pay roughly double Medicaid's daily rate for regular nursing home care. Later, he was relegated to a unit with so little staff that he rarely left bed. Finally, in spring 2012, when he was showing signs of dementia, Kateri declared him a permanent resident and moved to take his whole income.

At the last moment, Ms. Stefanides cobbled together his escape: She persuaded Gentiva Health Services, a national company, to provide eight hours of home care on weekdays — much less than the live-in care he had before — while her husband, still freelancing, signed papers promising to do the rest. In reality, the schedule relied on her visits and a neighbor's vigilance.

They managed, barely, for a year. But in 2013, they faced the same problem, only worse. The home care company, under new ownership, dropped her father, and NewYork-Presbyterian Hospital sent him for rehabilitation — to DeWitt.

"When the elevators open, you get this terrible stench," Ms. Stefanides

said of DeWitt's upper floors at night. "I was hearing people screaming for help and nobody coming. My father was on the verge of tears — in his defecation for three hours, and he kept ringing the bell."

(DeWitt's lawyer, Neil Ptashnik, now says: "The only comment the facility has is: We're well run, adequately staffed, we've had no problems with the Department of Health, and our residents seem quite happy.")

The nursing home sent him to the hospital after 10 days, with a recurrent infection from an improperly placed catheter, medical records show. The hospital soon discharged him to the next nursing home, Jewish Home Lifecare, where orders for therapy and skilled services brought the price of his care up to \$682.48 daily under Medicare.

Ben Taylor, a lawyer at the New York Legal Assistance Group, thought he could break the cycle. By law, he said, the state should require Gentiva to reinstate eight hours of daily home care pending a fair hearing. Meanwhile, Ms. Stefanides should contact managed-care plans, which were not supposed to rule out round-the-clock home care.

But she reached receptionists who said 24-hour care was unavailable. Jewish Home insisted her father could not safely go home with less. And day by day in the nursing home, he was sinking.

On arrival May 22 last year, Mr. Andrey was "alert and verbal," with a good appetite, clinical notes said. Less than a week later, he was eating only half his food. On Day 12, he was found on the floor: He had fallen from bed, hurting his knee.

By Day 14, when Medicare had spent nearly \$10,000 on his care, a pressure sore was eroding the flesh of his right heel. Despite treatment, ulcers later covered his left buttock and feet. When physical therapy ended, the wounds became another reason for the institution to extend his stay, now costing Medicare \$585.49 a day.

In late July, Mr. Taylor won a state directive for Gentiva to restore home services, if the doctor approved. Separately, a social worker at one managed-care company, GuildNet, told Ms. Stefanides that Mr. Andrey might be accepted for home care if the nursing home agreed.

But the nursing home said he was too weak to be released. Instead, it transferred him to a long-term-care wing.

Nursing Home Limbo

On a Wednesday evening in mid-August 2013, in the dining room, Mr. Andrey poked at the lid of his ice cream cup with a fork. Beside him, a blind woman fumbled to find the food on her tray, the staff too short-handed to help. At the next table, a woman with dementia kept screaming. Mr. Andrey's voice could not be heard above the din.

On this wing, emaciated Alzheimer's patients wandered into his shabby room. From a skinny 138 pounds on admission, he was dwindling to 128.

"Why am I with these people?" he would ask his daughter. "Why am I losing this weight?"

"Dad, this is all through atrophy," she told him. "We have to get you moving again."

"They never move me," he answered. "I'm lucky if they come to change me."

On some days he went hungry, he told his daughter. Rushed workers left his food tray on the air-conditioner, where he could not reach it. Several times, he fell out of bed trying.

Medicaid now paid the home \$307.70 a day for his care, much less than Medicare did before. On Aug. 20, two days after his Medicare stint ended, so did his protein supplements. If his daughter wanted him to drink Ensure, the

staff told her, she should buy it herself.

In rehab, a psychologist had noted that Mr. Andrey brightened when he spoke of “the pleasure he derived from the arts.” Now there was not even a television in his room. Visitors found the bathroom filthy, garbage uncollected and Mr. Andrey left half-covered in a diaper. A friend, Dyandria Darel, was so appalled that she documented the scene in photos.

(Jewish Home’s chief medical officer at the time, Mark Levy, who secured Ms. Stefanides’s permission to discuss the case, strongly defends the care provided, calling it “professional, compassionate and well done.” At the same time, he said, “if you fit it all together from the perspective of Mr. Andrey, I don’t think the United States health care system did a great job of meeting his needs.”)

Mr. Andrey’s only hope of escape now was GuildNet, the managed-care company. He was interviewed; the apartment was inspected; both passed. But the nursing home’s assessment was missing.

One Sunday evening that summer, Ms. Stefanides and her husband found her father falling from bed, in agony from his contracted legs. His pain medication, Oxycodone, had been halted over the weekend — “doctor’s orders,” the head nurse said when Ms. Stefanides confronted her, adding something about preventing kidney damage.

“My father’s dying, put him on goddamn morphine!” Ms. Stefanides cried. The flustered nurse gave her a number to reach a doctor. But the one who picked up said angrily that he was off the clock, and hung up. Not until Monday could a doctor be found.

By then, Ms. Stefanides felt as though she were petitioning for her father’s release from prison. Another month went by. All told, four months, 11 days and \$61,033.62.

But at 6:45 p.m. on Oct. 2, 2013, Joseph Andrey left the nursing home by stretcher as a GuildNet enrollee, his daughter at his side. He was carried up the stairs to the old apartment, newly equipped with a special bed. Soon the smell of good cooking filled the air. An aide fed him with a spoon.

The first week, his daughter crowed, he gained five pounds.

More Than Aides Can Handle

It was the aides who mattered most and earned the least, Ms. Stefanides reflected. The primary care physician whom GuildNet assigned to her father never met him. The nurses who showed up to treat his deep ulcers kept changing. Yet the two aides who split the week as “live-ins” were paid so little by a subcontractor that they had to take second jobs, they told her.

Both aides seemed nurturing, but one, a recent immigrant, was inexperienced in washing a bed-bound patient. The other rebuked Mr. Andrey when he woke her up, his daughter later learned.

Nearly immobile now, his skin frayed and flesh gaping, he needed more care than they could give, especially at night. When an aide asked for more help, Ms. Stefanides first called the subcontractor, Allen Home Care, and then the GuildNet case manager.

The case was already too costly, she was told. In fact, a caseworker confided, the only reason GuildNet had taken her father was that he was not expected to live long.

(GuildNet declined to comment. Calls to the chief nurse and marketing director at Allen Home Care were not returned, but a team coordinator said, “We basically do what we’re told by the insurance company.”)

In theory, GuildNet was now coordinating all of her father’s care. In practice, he careened between the sleep-deprived aides and a dozen different doctors at NewYork-Presbyterian Hospital.

When he had trouble breathing, his aide called 911, and he went by ambulance to the emergency room. The aide was told to check back in three days for the results of a urine culture, but she forgot. The bad news reached the family 10 days late: The bacteria were resistant to his prescribed antibiotic. By then he had a septic ulcer in his scrotum.

The result: Emergency surgery, a different antibiotic, 13 days in the hospital (\$108,895.37), followed by a brief discharge home without pain pills or a refill for his antiseizure medicine — and a seizure that sent him back. Two days in medical isolation while doctors ruled out multidrug-resistant bacteria (\$20,721.82). Home again, increasingly incoherent.

On Christmas Eve, suffering chills, fever and mental confusion, he went back to the hospital for the third time in three months.

A Father's Question

“Thank you for keeping me alive,” he told his daughter, teary with gratitude, when he emerged from days of delirium. “When are you taking me home?”

He still wanted to live, she realized. But the doctors said there was nothing more to be done. Now they wanted him sent somewhere else to die.

She felt they were bullying her to disregard her father's wishes. “They almost told me I was wasting their oxygen and their medicine,” she said.

His sepsis would keep recurring. His system, likely colonized by bacteria acquired in health care institutions, was breaking down. Demented, contracted, hurting — he had no quality of life, doctors said, urging hospice.

But as the hospital's own social workers had explained, hospice benefits from Medicare came with a catch: Her father would lose all Medicaid home care. In home hospice, that would leave huge gaps, unless she could tend to him around the clock. The alternative was hospice in a nursing home.

Not that, she vowed, vividly recalling her mother's monthlong death in hospice at DeWitt, after a doctor said withholding liquids was "the humane way." Once, arriving for her daily visit, she had unthinkingly carried in a cup of tea. Not quickly enough, she hid it behind a curtain, seeing her mother pass her tongue over parched lips.

"She was suffering, and I contributed to that," she said, sobbing. "I will never forgive myself."

For her father, she was determined to do better. She told the doctors she needed more time to consider home hospice, and wrestled with her inability to make the open-ended commitment. School administrators had long since lost patience with her absences, and all but accused her of using her parents' health as an excuse to miss work. She had weeks to go until early retirement, and she had been postponing surgery to replace a hip injured in an icy fall.

The hospital finally proposed another option: Haven, a hospice inside Bellevue Hospital Center run by Visiting Nurse Service of New York. On Jan. 29, with her father unintelligible again, she reluctantly signed the papers.

The people who met them wore masks. Suddenly alert, her father grabbed her sleeve. "Don't leave me here," he said. "Something's going to happen here. Why did you bring me to Bellevue?"

A hospice worker strapped him down, looking for a vein. As the painkiller reached his bloodstream, his daughter saw him gasp for life. She ran out in distress, asking for a priest.

"My God, the last rites, you're at a hospice!" Ms. Stefanides said later. "No priest to be found."

(A Haven official later expressed deep concern, saying, "We are reviewing this case to make sure this is the isolated case we believe it is.")

As she and her husband took turns at his side, Ms. Stefanides's father

lived on — one day, two days. Death came the third morning, before she arrived, on Feb. 1 of this year, three weeks before his 92nd birthday.

The funeral home director told her the deep pressure ulcers on her father's body were the worst he had ever seen. The records she obtained showed that in the last year of his life, his care cost at least a million dollars. Was that the best, she wondered, that a million dollars could buy?

“He didn't die in his bed, and that's what he wanted,” she said. “I still feel that I let him down.”

After the wake, she stayed behind with his body. In a last rite of her own, she placed her hand on his chest and said the act of contrition: “Please forgive my father for all his sins.”

Nearby, on display, was his life in pictures: dashing soldier, dancing husband, loving and demanding father. Through the winter gloom, it still gleamed.

Jewish Home Lifecare, not NewYork-Presbyterian Hospital.

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