DEATH FOLLOWED NEGLECT IN GROUP HOME

[1N/5/6/7 SPORTS FINAL Edition]

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When Martin Szczepanski was 14, his older sister came home just late enough from school one day to see him being molested by two boys who thought it was sport to hurt the retarded Polish kid up the street.

It was 1948 in Bridgeport, and life was hard enough for the mentally retarded without the stigma of rape. So, afraid to report the crime and unwilling to entrust their son to outsiders, Martin's parents moved first to a Pennsylvania farm and, years later, into their daughter's overcrowded home in Connecticut.

For most of Martin's life, the Szczepanskis made sacrifices to avoid having to turn him over to the state Department of Mental Retardation. But years after their parents had died, Mary Ann Leseke, Martin's sister, finally had to do just that.

She's been regretting it ever since.

Martin lived for 65 years in his family's care. He was dead within 18 months after the state took over.

At first glance, none of the facts available to the public about Martin's death on Jan. 1, 2001, would give rise to suspicion. He did not drown, choke or fall victim to some unexplained accident, like many of the mentally retarded people identified in a Courant investigation, published in December, of group home deaths over the past decade.

The issues raised in the series prompted the legislature to launch an investigation and Gov. John G. Rowland to issue an executive order Friday that makes sweeping reforms in the way DMR investigates deaths. Particularly troubling to lawmakers was the secrecy with which the agency has conducted its death investigations.

In that respect, there are perhaps few greater illustrations of how difficult it is to assess the agency's oversight of the mentally retarded than the story of Martin Szczepanski.

He doesn't show up on DMR's official list of deceased group home clients -- apparently because he spent the last six months of his life in convalescent care due to neglect he suffered in the group home. His own family was never told the state had substantiated the charge of neglect.

By all outward appearances, Martin had lived a long life for someone with Down syndrome, and then died from a stroke.

If only it were that simple.

Fateful decision

Szczepanski means "woodchopper" in Polish.

It was a fitting last name for a man who, despite his limitations, was given some of the harder jobs on the 115-acre farm his family owned in Lake Como, Penn. There were 30 cows and Marty, as his family called him, always milked the hardest, orneriest ones because his hands were so strong.

Years later, at a family dinner, his sisters realized he'd plowed through a whole plate of lobster claws while they were gabbing in the other room -- he'd torn them off the lobsters with his hands and scooped out the meat.

So when Mary Ann Leseke went to visit her brother at the Allied Rehabilitation Centers' group home in South Windsor where he was living on June 17, 2000, she became alarmed when Martin couldn't return the gentle squeeze she gave his left hand. Indeed, it cemented the worry that had been nagging at her for days. After caring for her brother much of his life, Leseke knew something was wrong.

She probably knew him better than anyone in the world, except this mother.

She knew what his face looked like when he was tired. She knew how to cheer him up with old polka tunes and, if that didn't work, the company of his young nieces and nephews.

And, Leseke says now, she should have known better than to entrust her brother to a state agency.

But as she and her husband, Steve, grew older themselves and their arthritis worsened, it became increasingly difficult for them to care for Martin, especially if he fell. So, when her oldest daughter in Florida needed help in September 1999, Leseke put Martin in the DMR- operated Hartford Regional Center.

There were problems with his care at the center from the beginning, as far as Leseke was concerned.

For one thing, she said, Martin was spending most of his time in a wheelchair instead of walking -- an assertion DMR denies -- which made it difficult for him to return to their split-level home for visits.

Most troubling, she said, was DMR's decision to take Martin off Coumadin, a medication prescribed by his long-time doctor, Mitzubell Chowdhury. Coumadin, prescribed for Martin to lower his risk of having a stroke, is often referred to as a "blood thinner," but actually prevents harmful clots from forming in blood vessels.

Leseke says she suspects Martin was removed from the medication because it required vigilant monitoring and frequent blood tests, a charge the DMR physician, Paul Dolinsky, denied.

"Never have I made a decision about someone's use of a medication based on scheduling or administrative reasons," Dolinsky said. He cited patient confidentiality as his reason for not discussing why he took Martin off the medication.

Asked whether he believes it was the right decision, Dolinsky replied: "I'd have to know more about what caused the strokes."

Dolinsky's notes from that time, obtained by Leseke, indicate that the doctor spoke with Chowdhury and reviewed Martin's cardiovascular records before deciding there was insufficient reason for him to be on the medication. Chowdhury declined to comment.

A few months after DMR removed the Coumadin, Leseke said, Martin was moved from the regional center into the South Windsor group home and encountered a new health risk -- the staff's failure to provide him with a low-sodium diet.

"I offered to show them how to make the food. I offered to make the meals myself and freeze them," she said. "But they treated me like I was a nuisance. Then they would go to the grocery store and buy all this prepared food that was loaded with salt."

Records from the group home during that time do not indicate what Martin ate, and the president of Allied Rehabilitation Centers, Dean Wern, said he didn't know if staff provided a low-salt diet.

He also said DMR didn't tell his agency Martin was a stroke risk.

"I think Martin received a good level of care, based on the information we had at the time," Wern said.

Martin's sister doesn't profess to understand the intricacies of medical science, but she knows one thing: When her brother was taking Coumadin and eating low-salt foods, he didn't have a stroke.

Less than six months after he stopped doing these things, he did.

And even then, no one seemed to notice.

Missed symptoms

From June 3, 2000 -- when Martin entered the South Windsor home -- to June 11, the daily logs used by the group home staff to record their new resident's various ups and downs, health problems and behavior, describe a mostly cheerful, cooperative and healthy man.

"He has a great sense of humor," one worker wrote. "He ate 100 percent lunch and dinner. He stated that the meal was delicious," another recorded. "Martin joked a lot tonight."

But it was as if the sun rose on a different person the morning of June 12.

"Martin appears to have loss of feeling in left side," a worker wrote. "Martin grumbled during most of a.m. activities."

It got worse. Over the next seven days, staff would record a litany of health and behavior problems about the once-docile man.

June 13: "Adamant negative behavior. On-call [nurse] notified. Very abusive to staff -- called staff a bitch." Staff also filed the first of four incident reports that would be sent to DMR about Martin.

June 14: "Martin chose not to eat dinner this evening. He was also very rude to staff, telling staff to shut up and threatening to hit staff with a hammer. Spent the shift sleeping on the couch."

June 15: "Napped off and on while sitting on the couch. While doing p.m. care Martin balled up his fist and swung attempting to hit me." The second incident report was filed with DMR, after staff had to call police to help them get Martin off the floor of the van when he refused to be taken to his day program.

June 16: "Refused to do anything even when offered help. He refused to eat."

June 17: "Martin had 5 changes with diarrhea from 12:30 to 11:30 p.m. No strength in left hand and leg. Sister visited and very concerned. Called Melissa [Giambra, the group home LPN on duty] and she spoke with her." A third incident report was filed with DMR after Martin fell out of bed and couldn't get up.

June 18: "Martin fell out of bed at 9:45 this morning. Unable to walk or stand on his own. Refused all meals." The fourth incident report was filed.

And, finally, June 19: "Martin got up -- screaming and yelling at staff to leave him alone. Threatened staff to punch her lights out and kill her."

Not once during these eight days did anyone at the group home take him to a doctor, despite his symptoms and Leseke's repeated insistence to staff that her brother had suffered a stroke.

Leseke said the nurse, Giambra, told her she believed Martin was either "faking it" or depressed.

By the time Leseke arrived at the group home the morning of June 19 and arranged for Martin to be transferred immediately to St. Francis Hospital and Medical Center, he was severely dehydrated and diagnosed as having had at least one stroke in the previous week.

Doctors at the hospital told Leseke her brother would not have lived through the week if she hadn't acted when she did. That is small comfort to her now, when she thinks about the final months of her brother's life -- essentially incapacitated in a nursing home, unable to walk or see and too frail to undergo the cataract surgery that had been scheduled before his stroke.

"You couldn't really call it a life," she says. "I was praying for God to take him."

Neglect found

Leseke said she heard from the state Department of Mental Retardation once after her brother died.

Someone from the department called to get her permission to have an autopsy performed on her brother. She refused, she said, because she no longer trusted the state agency to act in her brother's best interests.

"I thought he'd been through enough," said Leseke, adding that she didn't believe an autopsy would tell her anything she didn't already know about Martin's death.

But it turned out there was quite a lot she didn't know.

Before her brother was even discharged from St. Francis, DMR had received an allegation of medical neglect in connection with Martin's care. DMR officials would not discuss the case with a reporter, but issued a response to questions The Courant submitted in writing.

DMR said it instructed Allied Rehabilitation Centers, the nonprofit company that ran the group home, to investigate and provided a trained registered nurse to assist the company in its inquiry.

DMR said it routinely allows group home operators to conduct their own investigations unless the state believes "they cannot do an objective investigation. After Allied determined that neglect had, in fact, occurred, DMR made a "number of recommendations to Allied in regards to their policies of care," DMR said.

Allied disciplined two workers responsible for Martin's care. One was the registered practical nurse, Giambra, who still works for Allied as a "behavior specialist," Wern, Allied's president, said.

Wern would not name the other Allied employee or provide details about the discipline the two received, except to say it was "short of termination." Neither employee works in health services any more, he said.

Giambra said she could not discuss Martin's case without her employer's permission. Although she no longer works as a nurse for Allied, her license with the state Department of Public Health is still valid.

Public health officials said no disciplinary action has been taken against Giambra and no actions are pending. DMR said it never reported Giambra to the health department, because that "is the responsibility of [her] employer."

Leseke learned about the neglect finding for the first time last week -- about one year and a month after her brother died. She was told not by DMR or Allied Rehabilitation Centers, but by a reporter.

And although Leseke never called or wrote DMR seeking information after her brother died, she did demand Martin's records from Allied Rehabilitation Centers and expressed her anger to his DMR caseworker.

"I want to make sure they don't just sweep this under the rug," she said. "I want to know that the people who were disciplined for doing this didn't just get a week off with pay."

Illustration

PHOTOS: 2 (b&w); STEPHEN DUNN / THE HARTFORD COURANT; Caption: MARY ANN LESEKE , above, is still mourning the loss of her brother, Martin Szczepanski, below, who died after the Department of Mental Retardation transferred him to a group home. A DMR inquiry has found that neglect played a part in Szczepanski's death. Behind Leseke is her husband, Stephen Leseke.

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2 (b&w); STEPHEN DUNN / THE HARTFORD COURANT; [Mary Ann Leseke] , above, is still mourning the loss of her brother, Martin Szczepanski, below, who died after the Department of Mental Retardation transferred him to a group home. A DMR inquiry has found that neglect played a part in Szczepanski's death. Behind Leseke is her husband, Stephen Leseke.

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