

MIRACLE | Army veteran grows increasingly isolated from the world, rarely going out

Continued from Page A1

numb, the result of an AIDS-related condition called neuropathy, making simple tasks — opening jars, even a bag of potato chips — a challenge.

Some mornings he's too exhausted to leave his bed.

Yet he's grateful for the time still ahead of him, however much that is. He's made his peace with God.

"I enjoy every day that I get up," he said. "That's a miracle."

Seeking solace in God

The recent weeks have been hard on Michaelree.

Bethany Place's executive board, in the wake of federal budget cuts, voted last month to shut down the residential center that provides a home for Michaelree and four other men with AIDS. Some money from the state has given the center a temporary reprieve.

But Michaelree, an Army veteran, had already been there 16 months. The maximum a person can stay is two years.

Before coming to Bethany Place, Michaelree almost died after falling into a coma. He spent the next seven months in a hospital. After he awoke, the Department of Veterans Affairs moved him to a nursing home in St. Louis.

He hated it, mostly because he says he was treated like an invalid and surrounded by old people. He doesn't want to go back.

"This has been like a safe haven for me," he said of Bethany Place. "I stay here, I go to my doctor or I go to my church. Those are the only things I do."

Michaelree goes to church a lot.

As he grows increasingly isolated from the world, he attends Mass three or four times a week, either at the St. Elizabeth's Hospital chapel or nearby at St. Peter's Cathedral.

Seated in a pew on a recent weekday afternoon, he reflected on his life, his nasally voice echoing in the massive cathedral.

"It's my fault I'm in the position I'm in," he said. "But I give God all the credit in my life and am making the best out of a bad situation. And I pray every day."

'A very unpleasant place'

Michaelree isn't sure exactly how he got infected with the HIV virus. It could have resulted from unprotected sex with prostitutes while he was in the Army.

It could have resulted from an infected needle he might have shared during his years as a heroin addict.

But once he knew he was HIV positive, "I would hide my needles so nobody else would get it," he said. "There would be friends who'd say, 'I don't care, I'll take the risk, and I'd go, 'I won't.'"

Michaelree has six sons, all of them grown, from a wife and several other relationships. His sons' whereabouts are a mystery, he said.

"I have no contact with them," he said. "I wasn't part of their life coming up."

He acknowledged not using condoms.

"I didn't know what it meant, exactly, the government didn't even know what it meant at that time," he said of AIDS. "But I advised everybody involved to get blood work taken, which they did. And nobody was infected, and that's a blessing."

Michaelree wished he had done things differently.

"But I'm stuck where I'm in," he said. "It's a very unpleasant place to be."

Options are limited

At first, Michaelree wasn't happy with the news that he will have to move out of Bethany Place in a few months.

"It's a big step backward," he said glumly as he smoked a cigarette in the outdoor break area.

Michaelree, who served in Vietnam and Germany, looked off in the sunset. A tattoo of the Grim Reaper decorates his left arm. A studded gold earring hangs off his left ear lobe.

Michaelree's options for a new home are limited because of his intensive needs.

AIDS has weakened his im-



Bill Michaelree eats his lunch at Bethany Place. As a result of the side effects of his medicines, he has trouble eating.

mune system. The 40 or so pills he takes each day to deal with the side effects of the anti-AIDS drugs have left his body a wreck.

Sharon Smith, Bethany Place's executive director, reminds him that his move to Bethany Place was not meant to be permanent. Nor does it offer the sort of round-the-clock care that Bill needs.

"And Bill has reached the point where he needs that now," she said.

Michaelree acknowledged things weren't going well for him, physically at least.

"My memory's getting a lot worse, I'm way too wobbly on my cane," he said. "It's not easy watching yourself go backwards."

A week later, Michaelree interviewed for an apartment at a residential care center for people with AIDS in St. Louis' Central West End neighborhood. But drug problems among center residents made Michaelree, a recovering heroin addict, a poor candidate, and the center rejected him.

In late September, Bethany Place had found a new home for Michaelree — a small house only a few blocks away that he will share with another man who has AIDS. Personal assistants will provide the more specialized care Michaelree needs.

Michaelree acknowledged some fears about finally leaving Bethany Place. It'll be the first time he's lived outside a group home in a decade.

"It's going to be a challenge," he said. "This will be the first time I'll be doing it as sick as I am.... But I think it'll be OK."

A life of holy indifference

Michaelree is a survivor.

He has survived AIDS for a quarter century — since even before there was a name for the disease that has killed tens of millions of people worldwide.

He has survived long-running battles with Hepatitis B and C, which have assaulted his liver, interfering with the medications he takes to keep the AIDS virus at bay.

He survived a bout of AIDS-related pneumonia that sent him to a St. Louis hospital in August for 10 days, including five days in the intensive care unit.

He's lost 33 friends to AIDS. About three-fourths of them died after going off all of their



Above, Michaelree gets his medication patches from personal assistant "Karen," who declined to give her last name. At left, Michaelree takes a portion of the drug cocktails that he takes because he has AIDS. Above, Michaelree displays some of the pills he takes in a single day.

PHOTOGRAPHS BY ZIA NIZAMI

drugs except painkillers, he said.

"They were tired. Tired of living a life like the life we have to live," he said. "You're not accepted by the majority of people. Nobody sticks out their hand to welcome you to their house."

Today he has few friends.

"So I made peace. God is my friendship today," he said. "I can't see him. But I can hear him. He'll talk back to me. I know he's there."

Ben Stern, a Catholic seminarian serving a one-year internship at St. Peter's Cathedral, began visiting Michaelree at

Bethany Place in July.

Michaelree's impact on him over these past few months has been profound, Stern said.

"You know, when I was going out there and speaking with him, it seemed almost like I was somebody being ministered to," he said. "Seeing his faith really kind of awakened me."

Michaelree realizes his life, despite its many hardships, is a gift, Stern said.

"And I think he's come to the realization of what a lot of saints have, and that's called holy indifference," he said.

"And they're just putting it in

the hands of the Lord and saying ultimately, 'Your will be done, and I don't care how it's done, just let it be done for me.'"

One visitor at a time

Michaelree rarely ventures out into the world anymore.

Instead, it comes to him, one visitor at a time. Visitors such as Karen, his personal assistant.

Every two days, Karen, who declined to give her last name, drops by. She accompanies him on his visits to the Veterans Administration Hospital in St. Louis, where he sees an internist and a psychiatrist.

She is his lifeline to the outside world. She listens in on what doctors tell Michaelree, whose short-term memory has eroded.

"And if he needs to vent, or if he's depressed, he can call me," she said. "I'm there to listen."

She checks on Michaelree's medications and makes sure he's eating right. She also changes the pair of pain patches taped to his abdomen, which has been swollen by a condition called lipid dystrophy, a common side effect of anti-AIDS drugs.

The pain patches are a god-send for Michaelree, who, up until a decade ago, worked as a hairdresser in South St. Louis until the progression of his disease made it impossible to make a living.

"They can't repair nerve damage," Michaelree said. "They can only cover up the pain."

Costing more than \$800 a pop, the bandages are laced with fentanyl, an opioid pain medication that is released slowly into his body through the skin.

The pain reliever counters the agonies of his advancing disease, as well as the side effects of the scores of pills he takes daily to combat it.

One of the most insidious consequences is the gradual death of his nerve cells. This results in a constant, uncomfortable tingling in his fingers and feet.

Another symptom is the open sores that afflict his stomach and other internal organs.

"All my organs, minus my kidneys, have open lesions," he said. "It hurts."

The monthly cost: \$3,224

In the group kitchen area of Bethany Place recently, Michaelree opened a rectangular pill box with more than a dozen compartments. Each contained a mini-pharmacy of pills, some round, some bean-shaped.

There are some orange pills called Sustiva, known as a non-nucleoside reverse transcriptase inhibitor, which attacks the life cycle of the AIDS virus. He takes it daily, at more than \$450 a pop. It makes him feel nervous and edgy. Worse, it makes it hard to sleep.

"It gives you the most wild dreams," he said.

There are other pills, such as Viread, which costs \$462 a pill; and Epivir, which he takes twice a day, each pill costing more than \$300.

All told, Michaelree's anti-AIDS drugs, as well as other medications, cost \$3,224 a month — or more than \$38,000 a year, billing records show.

As a veteran, the federal government pays for all of his medications.

Michaelree doesn't see much of his family anymore. His father, with whom he is reconciling, has never visited him at Bethany Place. His mother, a cheerful woman of 73, comes about twice a month.

During one visit, they talked about the side effects of his anti-AIDS drugs — the damage to his teeth and gums, forcing him to look hard for a dentist who will see him. The list is short.

"And he had perfect teeth before this," his mother said.

"The medicine makes your gums recede," Michaelree said. "All the AIDS medicines cut up your teeth real bad."

Planning for the end

Michaelree's already planned his funeral.

It will be at Jefferson Barracks National Cemetery in South St. Louis County.

He isn't sure where his grave will be, just as long as it's "out there with the deer," he said.

He plans to give away as many of his body's organs as he can, a decision that took shape a few months ago when Illinois became the first state in the nation to allow people with AIDS to donate healthy organs.

"Both my kidneys are in good shape, and I'm going to donate those," he said.

Still, despite the pain, the hassles, the sheer struggle of living with AIDS, he wants to hang on.

There's his mother to think about, after all.

He can't die until she does. Simple as that.

And who knows when that will be?

"Hey, I might live a couple more years," he said.



Michaelree leaves Bethany Place for his new home in Belleville. In late September, workers at the group home found him a small house he will share with another man who has AIDS.