

# when your loved ones are infected

Bishop “Fritz” and Etta Mae Mutti

**W**hen a member of the family is infected with HIV, the whole family rides an emotional roller coaster. When two members of the family are living with AIDS, the roller coaster has loops. Our middle son, Fred, called us to say that he had been diagnosed with AIDS.

Later our oldest son, Tim, sent us a letter to tell us that he, also, was living with HIV. For about three years the five members of our family lived with incredible emotional ups and downs.

Here are some notes from Etta Mae’s Journal, which illustrate a few weeks in the journey:

May 17, 1990. Called Fred tonight and found him almost too weak to talk. I asked him if he thought he should be in the hospital and he said yes. Fred said, “I can’t ride in a car; I must have an ambulance.” My heart nearly stopped! Fritz and I immediately began packing and making travel arrangements so we could leave on Friday for New York.

June 4, 1990. Dr. Coyne came in while we were there today and said he would take Fred off all the antibiotics and see how he does for a couple of days before letting him go to Missouri . . . Fred thinks he will only be in Missouri for two or three weeks . . . No one has the heart to tell him that isn’t going to happen.

June 8, 1990. Fred stood the flight to Kansas City extremely well.

June 19, 1990. Picked up Tim at the airport. Tim will be here for three days—he wanted to come and see Fred. He seems to be feeling pretty well. I notice he doesn’t move very fast and

takes a lot of medicine . . . He says his feet are numb, and he admits to being tired all the time.

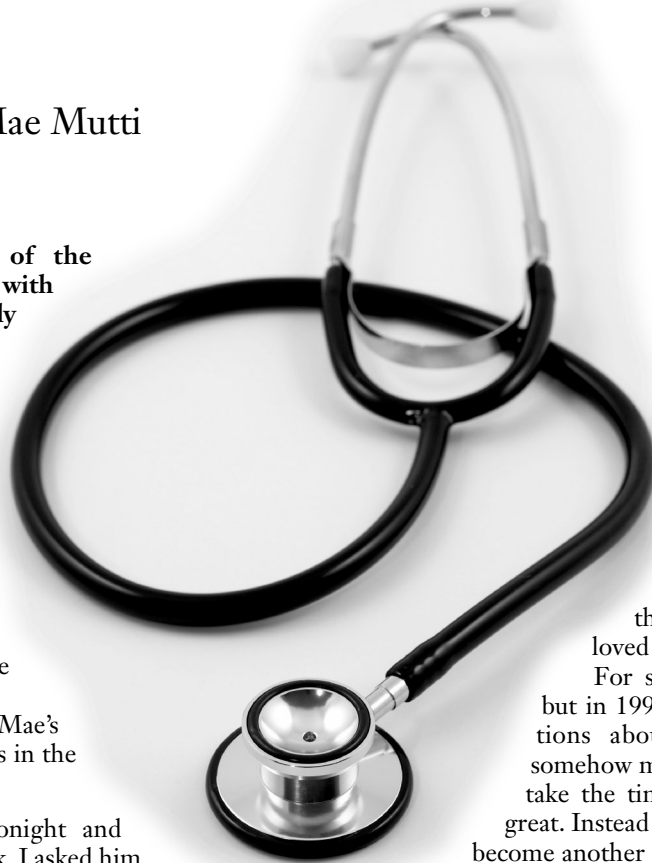
In spite of the uncertainty and the strain, we decided to try to live our lives as normally as possible. Of course there weren’t any normal days. Hope and despair hung over every day. Faith and fear mixed together. A sustaining source of strength was the calls and prayers of scores of loved ones and friends.

For several years Fritz kept a journal, but in 1990 he stopped recording his reflections about the long, hard journey we somehow managed. He says he decided not to take the time, but perhaps the pain was too great. Instead of helping, the writing process had become another burden.

None of our three sons kept a journal, so it was difficult to know what they were thinking as they struggled to endure. One record we have from Tim is a calendar. Here are some notations from his last weeks in 1990:

October 1 . . . . . Order pentamimine  
October 4 . . . . . 12:00 Bod Dean; 2:00 Dr. Thompson  
October 6 . . . . . AIDS Quilt at Emory  
October 7 . . . . . Order AZT  
October 23 . . . . . Dr. Randolph  
November 6 . . . . . Social Security appointment  
November 12 . . . . . Radiation  
November 30 . . . . . Dr. Thompson  
December 10 . . . . . Endoscopy

The frequent appointments for treatments indicated that Tim’s health was declining rapidly. He was looking forward to



Christmas that week. He had noted in his calendar that Marty would arrive in Atlanta on December 21 and that Fred would come on December 22. Neither made the trip because Tim died on December 21, after a long and valiant battle with AIDS.

The next nine months found us keeping in close contact with Fred as he went in and out of the hospital. He decided to move to Florida where "there was sunshine and flowers and grass." The decision was not to our liking, but we were determined to support his desire. It meant changing doctors, finding a place to live, making new friends, etc. all while he was extremely ill. However, he made the move and almost immediately was diagnosed with toxoplasmosis, an ailment which caused him to develop dementia. He continued to know who we were when we called, but couldn't remember exactly where he lived. He told his mother one time when she called that he was going home that day. When she asked where home was, he replied, "I don't know, but it isn't here."

On September 20, 1991, Fritz received a phone call at work saying Fred had gone into a seizure and had been taken to the hospital. Prayer concerns began to flow around the table for us and for Fred. Fritz recalls: "Halfway around the table Linda came to say I had another call. This time Sandy had to tell me that Fred had died. We knew it was coming; he looked so bad on Labor Day. But we didn't expect it so suddenly. I went to Avondale for the awful task of telling Ett. She knew when she saw me."

Throughout this roller coaster life-and-death ride, friends and church members were there to hold our hands, allow us to pour out our feelings, offer food as a source of comfort, and pray with and for us. As we struggled with the fear of having our sons judged and ostracized, we told our story to only a few friends. When we told more and more

people, we found there was much more openness and support that we had anticipated.

As we flew back and forth to Atlanta and New York, we were offered credit cards, money for prescriptions, and companionship. Rented cars and restaurant meals were provided for us while we stayed in New York to be with Fred. As we grieved after the funerals, people made available to us a condo for a retreat place. We were also asked if we needed someone to help hold the charge conferences that Fritz needed to conduct. We were told that Hawaiian lei had been placed on the ocean in memory of Fred and a tree had been planted in memory of Tim. All of these acts of kindness and love warmed our hearts and made our grief become more bearable.

Throughout our long struggle with AIDS we grew in faith and were able to put our lives in God's sustaining care. As life continues we are able to declare with Saint Paul: For (we are) sure that nothing can separate us from God's love" (Rom. 8:38-39 cev). □



Bishop Albert "Fritz" and Etta Mae Mutti, Kansas City, Missouri, are coordinators of the United Methodist Global AIDS Fund. Bishop Mutti served twelve years as the episcopal leader of the Kansas Area. After the

death of their two sons, they wrote *Dancing in a Wheelchair: One Family Faces HIV/AIDS*.

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