

A New Dream: To Help PWAs Who Are Alone

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Mary and Bill beseech me to tell other parents not to try to face this crisis alone.

"Bobby has given us strength, but we need so much more," Mary said. "We need other people to talk to — other people going through the same thing."

Bill agreed: "I think other people may need us more than we need them, at least just as much."

Mary shared her dream with me — to help care for AIDS patients who have no families to support them. "It's something I want to do when when Bobby is gone." She admits she isn't sure she will have the courage. Somehow, I think she will.

When Bobby was diagnosed with AIDS, a minister who happened to be in the hospital at the time came to comfort Mary as she sat in the lounge and cried. "I told him it's such a difficult thing — not the AIDS or even the reaction of people to it. What bothers me is that my child is dying and there is nothing I or anyone else can do about it."

Bill echoes her frustration: "There is no amount of money — you can be the wealthiest person in the world, and that money can't help if you have a son who has AIDS."

How do they cope with that helplessness?

"I hope and pray," Mary said. "We pray that the scientists and the chemists and the research people come up with something." Bobby missed by one slot a chance at the AZT trials that started last May. The drug has since been approved by the FDA and he now receives the costly medication.

Last Thanksgiving, Bobby, back in New York, was once again hospitalized. The drug Pentamamine used to treat PCP played havoc on his body. After 14 days of treatment, his kidneys and bladder were not functioning.

"He would pass out every time he sat

up," Mary said. "They decided to do another spinal tap because they suspected these were seizures. I was with him this time. After a few weeks, they stopped the Pentamamine. It had cleared up his lungs completely. Then we had to get the kidneys functioning properly, and so he was in the hospital for another week."

Bill and Bobby's brother Sam came to New York to help Bobby move back into his apartment. His pancreas was no longer producing insulin, so he had to learn to inoculate himself.

Mary returns to her photographs. She shows me each one.

"There is so much love for him. I love all my children, including Bobby. All of the horrible times we have gone through with him — his suffering so much, accepting his homosexuality and him. But he is our special child and his brother and sisters' special sibling. It's hard on them all."

Bill and Mary feel Bobby is fortunate in ways. He maintains his own apartment with financial assistance from Social Security disability, Medicaid, private insurance and the New York City Department of Social Services (DSS).

Bill asked me if I would like to see a videotape Bobby made in New York for DSS — his way of reaching out to other AIDS patients.

We watched in silence. I saw in his gaunt face a boyish smile. I saw his father's eyes and heard his mother's laugh. I felt numb as I drove home that afternoon, scarcely noticing the cold, monotonous winter rain.

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AUTHOR'S NOTE: Bobby still lives in his New York apartment. He has agreed to meet with me so we may report his personal postscript to this series in next month's Q-Notes.

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