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A Mother's Death: The Story of "Margaret's" Children

Christine Mitchell

Christine Mitchell, RN, is the Director of the Office of Ethics at the Boston Children's Hospital, an Ethics Consultant at several of the Harvard teaching hospitals, and a Faculty Member in the Division of Medical Ethics at Harvard Medical School in Boston, Christine.Mitchell@childrens.harvard.edu. © 2006 by *The Journal of Clinical Ethics*. All rights reserved.

On Mother's Day, I sat down with "Margaret's" three children to talk about the way she died. They are all young adults — two daughters, "Mary" and "Martha," and a son, "Paul." We met in their home — the house these children had grown up in and taken care of their mother in for five years, which Paul bought so his mother could stay there. It had taken awhile for all of us to find a time to get together, and the irony that it turned out to be Mother's Day was not lost on any of us. "Somehow," one of her daughters said, "it seems right."

Their mother, Margaret, died at the age of 54 of severe progressive Alzheimer's disease that had left her speechless and increasingly agitated and defensive. When she started falling and becoming hard to control, her children brought her to the hospital. After a few admissions and discharges at a general hospital, she was admitted to McLean Hospital, a locked ward in a residential psychiatric facility where her behavior was less disturbing to others. Lots of medications and electroconvulsive therapy were tried over several months with little therapeutic benefit. Still, she was restless, yelling and pacing, and so difficult to feed that she dropped several dress sizes.

Her children believed she was suffering and thought she would never have wanted to be kept alive in this undignified state. They asked if she could be given something to relieve the restlessness, to keep her calm, and enable her to die peacefully. Some of her doctors and the children thought morphine was probably the best drug to use, but many nurses objected to medicating Margaret with opioids just to keep her calm. They were used to restless, inarticulate, emotionally labile patients like Margaret. They were not experienced in "end-of-life care" and were not accustomed to giving large enough doses of opioids to ensure a peaceful death. They asked for an ethics consult. There were differences of opinion about whether Margaret was actually suffering, about whether she should be medicated with morphine, about whether she was dying or even should be allowed to die sooner rather than later, and about whether a psychiatric hospital was the best place for her to die.

The children met with the ethics committee, talked with various staff, and even wrote a letter, requested by the ethicist, to explain their values, beliefs, and wishes for their mother's care and death. Finally, the children, the ethics committee, and the staff agreed that it would be best to transfer Margaret to a residential hospice, and she was evaluated for "terminal sedation" — giving morphine often enough and in large enough doses to keep a patient unconscious, and thereby pain-free, until she dies. In the end, terminal sedation was

not needed, but enough morphine was used to keep Margaret calm. Ten days after she walked in the front door of the hospice, Margaret died peacefully with some of her family around her. In the following pages, you will read about Margaret and the ethical concerns that came up in deciding what constituted good care for her from the perspective of her physicians, Julieta Holman, MD, and David Brendel, MD, PhD, at McLean Hospital, and Rosemary Ryan, MD, at the hospice, and from the perspective of her children expressed in a conversation I had with them more than a year after Margaret's death.

Note: Throughout this case, the names of the patient and her children have been changed. Quotation marks have been used around these changed names at their first appearance in an article. No other information has been masked or changed in this case. The information presented in this case is used with the permission of the patient's children and the other parties involved.