# Bill White

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"While Bill's choice is unquestionably painful for those of us who have become his friends, we must respect the decision of a capable, mentally competent individual to refuse further treatment under New York State law," it stated.

"Bill had hoped that his decision would be a private one – between himself, his family and friends. Strong Memorial Hospital understands that end-of-life issues are, and perhaps always should be, controversial. It is our hope that Bill's choice will be treated with the dignity that Bill desires and the thoughtfulness that each of these heart wrenching situations deserves."

D'Agostino further explained that over the last few weeks White "had been beginning to talk about wanting to make a decision" about ending the ventilator treatment. The staff waited to respond, but eventually, she said, "He made it clear he was very serious."

White's condition was deteriorating, as was his ability to function, the statement noted. Strong put together a team of psychiatrists, ethicists, physicians, nurses, a social worker and patient advocate to consider White's request, D'Agostino explained.

The team made sure that he was competent, she said.

"We are bound by the law," she noted. "The patient has the right to refuse treatment. Our view is Bill allowed us to care for him 32 years and has the right to ask us to stop."

According to Jeffrey Spike, Ph.D., chair of the hospital's ethics committee, it is not uncommon for a patient "on some kind of machine that keeps them alive" to decide to discontinue treatment, knowing that decision will lead to his or her death.

"It probably happens a lot, but people don't hear about it a lot. It's very personal decision" between the patient and physician, or care team, he said.

"The basic issue is, 'Does a competent adult patient have the right to refuse treatment?'" Spike asked rhetorically. "That has been decided by courts in every state. Yes, a competent adult patient does have the right."

The ventilator is simply another medical treatment, he said. It was invented in the 1950s primarily for people paralyzed by polio. In most cases nowadays, it is used to get a person through a medical crisis. A paralyzed person who remains on a ventilator for a long time becomes quite vulnerable and weakened, suffering medical complications.

## Whose decision?

"My body is worn out," White told the *Courier* Aug. 8 during a brief interview in his hospital room. He was quite lucid, and talking with his sister and McBride.

He made it clear that the hospital should not be held accountable in any way for the path he has chosen.

"The one thing this hospital wants is the best thing that benefits me," White said. "They've always wanted the best for me."

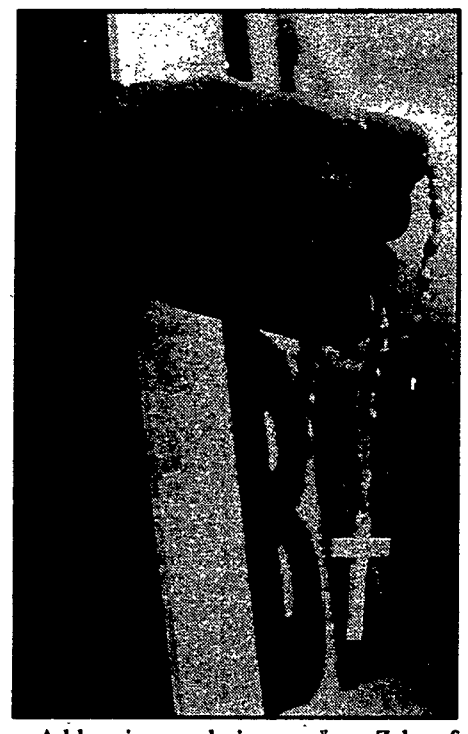
He declined further comment, saying that no matter what he said, people would disagree with him or misunderstand him.

White had been following media reports, including those of an Aug. 5 vigil outside the hospital. The vigil drew a number of people with disabilities, some of them sitting in wheelchairs. "Let Bill Live" read the signs many carried.

Bruce Darling, executive director of the Center for Disability Rights in Rochester, participated in the vigil.

Darling charged that the developing situation smacked of physician-assisted suicide, saying that White is far removed from being on the brink of death.

"What concerns us is that people with disabilities are unfairly targeted for physician-assisted suicide and euthanasia," Darling said. "At what point does your life stop having value – when you're on a ventilator, in a wheelchair or when you have a limp?"



Addressing such issues, Lyn Zyla of Catholic Charities Community and Residential Services, said, "Basically any type of case like this is an individual case. So we would never presume to speak for all people with disabilities."

However, "We have a clear understanding of what the Catholic Church position is on cases like this," Zyla said. "He is not asking to commit suicide. He is asking that the extraordinary means to keep his life going be stopped.

"Bill has the same rights as every citizen of our society, whether he has a disability or not. We need to be thinking of it in terms of being Bill's decision."

White's sister, Dianne White of St. Petersburg, Fla., also said that she did not consider her brother's request to be a case of physician-assisted suicide.

"It is absolutely not true," she said. "He's loved by everybody in the hospital. We know if he changes his mind, there would be a huge party here."

Regarding what has become a public debate about her brother, she said, "The people out there are making judgments based on lack on knowledge."

District Attorney Relin, who said hospital officials contacted his office Aug. 4, expected to finish his review of the situation soon. He had not yet rendered a decision as of the *Courier's* press time on Aug. 10.

"This is an area of the law that's a difficult area," Relin said. "We are looking into the background, the status of the law in New York, what a hospital can and cannot do relating to situations like this. We will be checking with members of Mr. White's family, to see if he discussed the procedure with them. We want to be sure it is a rational and informed decision, not out of depression or a sense he should do this."

And, Relin added, "The hospital does not want to do anything that could be considered assisting him in suicide."

## Not 'gray'

Although not directly involved, diocesan Catholics were examining the meaning of the case.

"This is about somebody's life," said Suzanne Schnittman, consistent life ethic coordinator, told the *Courier*. "Bill needs to know everyone supports and loves him.

"Bill White is a person to the community. He's not a cause. He's not an issue. ... He is a citizen of the community, and we would mourn his loss deeply because he's a person, not because he represents a right to life."

"This is a tragic dilemma," said Sister Patricia Schoelles, SSJ, president of St. Bernard's Institute. "We need to recognize the tragedy inherent in decisions like this one."

However, Catholic teaching provides clear direction, she said.

"This is not a gray area. Nobody has to accept treatment they don't want."

Catholic teaching avoids two extremes, she stated: "First, that of absolute vitalists, who would want to keep people alive at any cost, beyond even when their life is of benefit to themselves, their families, or other communities to which they belong. The other is the extreme which holds that euthanasia, suicide or assisted suicide are justified for individuals because they are sick."

Marvin Mich, an author, theologian and a parishioner at Rochester's St. Mary's Church, said there should be no confusion between a case like Bill White's and an attempted suicide. In a case like White's, "the intention is not to cause death but to accept the natural processes, and that's a whole different thing," he said.

Mich, Schnittman and Sister Schoelles noted that cases must be considered on an individual basis – but always with respect for the rights and dignity of the person involved.

Dr. James Wood, medical director for geriatrics for Via Health and former medical director at St. Ann's Home, noted that White's situation had prompted discussion among his colleagues.

"It's a good thing to have that conversation and dialogue," he said.

"My perspective is really to encourage dialogue between parents and children around these issues. ... It's a great relief to know the parents' feelings in these issues."

He also recommended that people designate health care proxies, through forms available at medical institutions, to help prepare for such situations.

A person cannot anticipate certain specifics that may occur, he noted, but a health care proxy form legally allows the person of your choice to speak for you.

# Key church teachings light way

Through the years, the church has offered guidelines on end-of-life issues.

"What the magisterium seeks to do is give general principles, norms within Catholic teaching that would apply to these cases," observed Peter Cataldo, director of research for the National Catholic Bioethics Center in Boston.

Every case has its own individual circumstances, he said. "Those responsible for patient care need to apply the principles and norms as found in the teaching."

He cautioned, "There has to be a balance between a patient or surrogate decision-maker's subjective judgment and objective criteria."

He also noted that treatment that is "medically ordinary" may still be considered "ethically extraordinary."

The center cannot comment on specific cases, Cataldo explained. But he encouraged Catholics to read pertinent church documents, excerpts of which follow. They are presented here in slightly different contexts from their original formats:

**1** "A person has a moral obligation to use ordinary or proportionate means of preserving his or her life. Proportionate means are those that in the judgment of the patient offer a reasonable hope of benefit and do not entail an excessive burden or impose excessive expense on the family or the community."

**2** "There should be a presumption in favor of providing nutrition and hydration to all patients, including patients who require medically assisted nutrition and hydration, as long as this is of sufficient benefit to outweigh the burdens involved to the patient."

**3** "We have a duty to preserve our life and to use it for the glory of God; but the duty to preserve life is not absolute, for we may reject life-prolonging procedures that are insufficiently beneficial or excessively burdensome."

**4** "Euthanasia must be distinguished from the decision to forgo so-called 'aggressive medical treatment,' in other words, medical procedures which no longer correspond to the real situation of the patient either because they are by now disproportionate to any expected results or because they impose an excessive burden on the patient and his family."

**5** "When inevitable death is imminent in spite of the means used, it is permitted in conscience to take the decision to refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due the sick person in similar cases is not interrupted."

**6** "(One) cannot impose on anyone the obligation to have recourse to a technique which is already in use but which carries a risk or is burdensome. Such a refusal is not the equivalent of suicide."

**7** "The free and informed judgment made by a competent adult patient concerning the use or withdrawal of life-sustaining procedures should always be respected and normally complied with, unless it is contrary to Catholic moral teaching."

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Quotations 1, 4 are taken from Pope John Paul II's 1995 encyclical *Evangelium Vitae* (The Gospel of Life).

Quotations 2, 3, 7 are taken from the U.S. bishops' 1994 "Ethical and Religious Directives for Catholic Health Services."

Quotations 5, 6 are taken from the 1980 "Vatican Declaration on Euthanasia," with substantial input from Pope Pius XII's 1957 "Address to those taking part in the ninth Congress of the Italian Anaesthesiological Society."