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Disabled

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pense on the family or community.(56)

"A person may forgo extraordinary or disproportionate means of preserving life." (57)

The right to forgo treatment is universal, Father Brodnick said.

"We have a duty to preserve life, but not at all costs," Father Brodnick said. "That's never been a part of church teaching. Is it morally imperative that we keep a person alive artificially? The answer is no. This holds true for all people, disabled or not."

"There is no separate set of rules and considerations for those who are handicapped and facing death," said Sister Patricia Schoelles, SSJ, a theological ethicist and president of St. Bernard's Institute in Rochester.

Doctors must abide by patients' wishes in such cases, Schiavone said.

"We are not mandated to provide treatment that any patient refuses," added Schiavone, who serves on the St. Joseph's Hospital ethics committee with Father Brodnick. Schiavone said that he has worked with disabled patients who refused treatment, but never with the fanfare that Bill White generated.

Just why did White's situation fuel so much controversy? Sister Schoelles said it extends from a stereotype that "Catholics try to keep people alive at all costs."

It's an image that Sister Schoelles, for one, doesn't care to uphold. While she said Catholics "have to stand opposed to abortion, (Jack) Kevoorkian and euthanasia," she staunchly disagreed with such groups as Owen's and the Rochester Center for Disability Rights, the latter of which petitioned the courts to stop White's death. Both organizations charged that White was not given options that might have persuaded him to feel differently, such as seeking a venti-

lator-dependent wheelchair.

"The dignity of a human being — the guy was trampled on by these groups," Sister Schoelles said. She said that White, who never sought public attention, unwittingly became a symbol and cause for the disabled-rights community. In addition, she said, his decision was second-guessed by people who had never met him.

Owen, on the other hand, said her views about White's case are based on years of experience of bias against the disabled community. Owen, 70, who is blind and partially deaf, has used a wheelchair for 25 years. In her opinion, people with disabilities are prone to becoming depressed and ending their lives, because they don't feel welcome by society.

"I've had to fire one doctor after another for saying, 'You're an old woman, you can't see; why don't you just go home (to vegetate),' Owen remarked.

Owen charged that euthanasia is "the most efficient, cheapest and effective way" for the medical profession to deal with treatment of disabled people. Schiavone acknowledged that health-care costs for disabled people are indeed massive when wheelchairs, catheters, ventilators and day-to-day care are factored in. However, felt that Owen's views are not representative of most of the medical profession.

"You can look at disabled patients as consuming resources. But that is not at all the attitude of the physicians practicing in Elmira," Schiavone said.

Whose choice is it?

What line must a disabled person cross in order to be judged as having a sufficient or insufficient quality of life? And who makes these determinations?

As professors, politicians, activists and theologians debate these issues, Father Brodnick pointed out that one faction's voice should be heard above all the rest: that of the disabled people themselves.

"Who are we going to give rights to? To society, or to the person (with disabilities)?" Father Brodnick asked.

Mary Talbo, a parishioner at St. Anne's Church in Palmyra, has multiple sclerosis and has used a wheelchair for 17 years. Her chronic illness is not terminal, but she said she may eventually become so debilitated that she would consider rejecting life-sustaining medical treatment.

If and when she is faced with such choices, Talbo said she would prefer that her wishes rank above those of doctors and family members.

"I wouldn't like people telling me I cannot die if I want to," Talbo said. "It's between me and God. I would really appreciate just to be left alone."

Regina Krolak visits Talbo as part of her work as an advocate for the disabled with St. Michael's Church in Newark. Krolak has a sister with Down syndrome and a son with mental disabilities, as well as a grandniece born with severe deformities.

"I can't imagine my life without them. Look at what I would have missed," Krolak said. She described her grandniece, now 8 years old and in second grade, as "the sweetest little thing in the world."

But if her son, for instance, became permanently bedridden, Krolak speculated that she might feel differently about whether he should go on living.

"If my son's quality of life was so severe that he'd lay with tubes in him the rest of his life, I wouldn't want that," Krolak said. "He'd be in a lot of discomfort and pain, and wouldn't understand what was going on. I wouldn't want that for myself, either."

However, Krolak said wouldn't seek to influence the decisions of a patients outside her family, such as Talbo.

"They have the right to that choice if they're capable of making it," Krolak said.

Sister Schoelles agreed that these decisions should be left up to the individual, or the person who has been designated as that

Directives are for all

Have you heard of an advance directive? Do you have one on file?

If not, don't delay, urged Father Joseph Brodnick, chaplain at St. Joseph's Hospital, Elmira. Regardless of age or health condition, any person can become incapacitated either gradually or suddenly. An advance directive, he said, gives you a say in medical procedures when you may not physically be able to speak.

The New York Public Health Law allows a person to select someone else as a contact regarding his/her medical condition. The designated person has the right to make decisions about treatment, services or procedures regarding a patient's physical or mental condition — including life or death decisions — if the patient becomes unable to understand and appreciate the crux of these decisions.

Proxy forms are available from your physician. Though two adults are required as witnesses when a proxy is signed, no lawyer need be present. You may revise this document as often as you wish.

Another type of advance directive is an "instructional directive," such as a living will. A living will is not legally binding in New York, but it can provide details about the patient's preferences for treatment decisions.

person's health-care proxy (see above).

"We shouldn't use the term 'quality of life.' Then that opens judgment up to society," Sister Schoelles said. "It should be, 'What's in the person's best interests?' Treat this patient not as a group, not as handicapped or retarded, but as an end in himself or herself."

Tutu

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lives for decades. He added that South Africa's transition to majority rule in 1994 was not marked by the cataclysmic violence many observers thought would happen when the country changed its government.

"The predicted disaster did not strike us," he said. "The blood bath did not hap-

pen. The world looked on, almost in awe, as South Africans stood in long lines as they snaked their way to the voting booths."

Archbishop Tutu, currently a visiting professor at Emory University in Atlanta, Ga., highlighted the international community's support for the anti-apartheid struggle, a support he noted was instrumental in toppling apartheid.

"You know, friends," he said, "we were sustained by the love and the prayers and

the caring of very many around our world. Without your support and your help, we couldn't have made it."

A longtime proponent of nonviolent struggle, Archbishop Tutu acknowledged that it wasn't easy to keep the faith during the darkest days of government repression in South Africa. However, he said Christians believe God oversees the course of human affairs, although it may be difficult to believe so at times.

"We are forever prisoners of hope," he said. "We know, despite all appearances to the contrary, that goodness is stronger than evil, that love is stronger than hate."

In a post-luncheon press conference, Archbishop Tutu spoke about his work with the Truth and Reconciliation Commission he headed from 1996 to 1998. The commission, set up by the South African government, granted amnesty to the perpetrators of violence and repression during the apartheid era, in exchange for their testimony about their deeds.

In November 1998, the commission released its findings, which stated that the former white-minority government used murder and other forms of terror to enforce apartheid, and that black militants killed innocent civilians and tortured opponents during the anti-apartheid struggle.

The commission also released recommendations designed to foster racial reconciliation, including the payment of reparations to victims of apartheid. However, the archbishop said the recommendations have yet to be implemented, and that the government's failure to do so has hurt the commission's efforts to reconcile South Africa's formerly warring communities.

"Many of (the victims) feel that the commission or the government ... has been more perpetrator-friendly than victim-friendly," he said.

One of the most dramatic moments in the commission's history came when P.W. Botha, South Africa's president from 1978 to 1989, was implicated by former government officers in the killings of eight anti-apartheid activists. Botha — who has denied knowledge of any security-force atrocities during his administration — refused to appear before the commission. A black judge ruled him in contempt of the commission, but white judges on a higher court overturned the lower court's ruling.

Archbishop Tutu said he felt sorry for Botha, and stressed that the commission wasn't out to get the former president.

"We were not sort of bloodthirsty," the archbishop said. "We just wanted to say no one was above the law."

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