

## SECTION C

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# The Babies Who Die In The Corner

**W**HAT IS the best way to kill a deformed infant?

They could be given any of a host of injections of substances which would — as the expression goes — “put them to sleep.” But actively helping an existing being to die is generally termed homicide and frowned on by the courts.

One could allow severely defective babies to live as long as they can — but without any medical attention whatsoever. The infant will eventually die of “complications” or “an act of God.”

But you can't predict when a complication, in the form of a stray germ or two, will materialize and very few people think they know when or what the Lord will do. And the passage of time causes a lot of anguish to the parents, who are sadly waiting for the inevitable.

So the most common thing to do is withhold not only medicine, but food.

The deformed infant is starved to death, and there are those who feel that since the infant stops crying after a day or so, he doesn't really feel any pain.

Or he is just too weak.

But until recently, the issue was not a public one. The infants died in the corner bassinets of countless hospitals and only those people directly involved were aware of it.

But last month, the state of Illinois, acting out of humanitarian concern and gut reaction, interrupted the planned death of Siamese twins. The state now finds itself in the position of having to decide, as a matter of policy:

- When is death preferable to life if the existence is going to be short, miserable, painful and costly?

- Who should decide when a newborn should live or die?

- What is the most humane way to bring about death — or, if the decision is life, what is the most humane way to treat a miserable infant who may die anyway?

- And in the case of Siamese twins, can the state allow them both to grow until they die? Or can it establish a policy to equitably determine which one shall die? There aren't enough internal organs for both.

It started May 13, when an anonymous caller told the Illinois Department of Children and Family Services that Siamese twins were being abused in the Lakeview Medical Center in Danville, about 100 miles south of Chicago.

According to department director Gregory Coler, investigator Patty Ferris visited the center, saw the starving Twin A and Twin B and the orders on the medical chart stating, “Do not feed in accordance with parent's wishes.” The parents were Dr. Robert Mueller and nurse Pamela Schopp, who work at the Lakeview hospital.

That the twins were still alive despite the order eight days after birth was because of the fact that another nurse defied orders, said Coler, and twice surreptitiously fed the unnamed boys.

Miss Ferris seized control of the twins and had them shipped to Children's Memorial Hospital in Chicago, where they were given a blood transfusion and food. They are currently alive, but how long that will last is unknown. They are joined at the waist, said Coler, and share a leg and intestinal tract. There may be two kidneys, but they may not both be functional.

Physicians at Memorial Hospital believe that there is not enough material for both to survive if an operation were ordered to separate the twins — and it is not yet known which one would have the better chance to live. Generally, with the separation of Siamese twins, the one with the majority of vital organs intact is given all the organs he needs to live independently — rather than have both twins die eventually.

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Which means that if the department's physicians determine that life is possible, the state will have to decide which will live. The state is not helped by the two court-appointed lawyers — one for each boy. One says the twins should remain in state custody. The other favors a return to the parents.

"This is the first time I am aware of that we have taken a child out of a hospital," said Coler. "But I became aware soon after we became involved in this case that letting the child starve certainly is not the issue at the hospital. The practice of making a decision about whether or not certain types of medical care should be provided to deformed children is a common occurrence.

"This has just been put before the public eye what has occurred behind closed doors involving life-and-death decisions about deformed infants."

Life is not, in and of itself, sacred. None of the world's major religions places an absolute prohibition against taking a life or allowing one to die. Religious philosophy tends to deal with the reasons for living and the manner of

dying. Everything has to have a reason and a moral justification. Killing is only wrong when there are other options available.

Doing nothing is not killing. It is an abrogation of the decision-making process. It involves letting someone else — in this case, the staff at the hospital — do what the parents felt ought to be done.

But then, they didn't have it in them to take the children home and look at them and talk to them and hear them whine and think about the futures they would have liked for them and think about the family they won't have and, at the same time, starve them to death.

But if they really thought it was right, they had a responsibility to do that.

If they could.

Circuit Court Judge John Meyer, in an extraordinary decision, ruled the hospital was guilty of negligence, but not the parents. In his custody ruling in favor of the state, he wrote: "Has our society retrograded to the stage where we mortals can say to a newborn, abnormal child, 'You have no right to try to live with a little help from us?' I hope not, and I

think not, although the evidence in this case appears to contradict me."

The judge was naive. Life-and-death decisions have always been made by someone. Usually, when the person is alone. And usually, it is a matter for him and his conscience.

What sets this case apart is the fact that the responsibility was ducked from the beginning — people who said they were morally correct passed the buck: the parents to the hospital administration; the administration, through anonymous orders, to a nurse. But at least she took a stand and slipped the kids some food.

Now it is the state's turn. They have the twins, and will have to act without regard to emotionalism and expediency. One of the boys will probably die. He can die with dignity and humanity. He ought to.

Which one will live is not yet known. But at least they have names. After the state was awarded custody, the parents petitioned the court to amend their birth certificates. For the time being, Scott and Jeff are living on the mercy of the State of Illinois.