

6/9/04 St. Charles Lodge Apartments: Living Will Talk - Robert E. Ruberg, Presenter

Mr Ruberg: Some 15 years ago or better, the Supreme Court of the United States in *Cruzan v. Missouri* upheld the right of a person to refuse medical treatment if they had a Living Will. In that case the Supreme Court justices found that a competent person has the right to refuse medical treatment, including artificially administered food and water and other life-sustaining measures such as respirators. They said they all could be refused as medical treatment.

Subsequently in 1993 the Kentucky Supreme Court decided the case of *Degreller v. Ellison*, where the mother of a patient who was in a vegetative state as a result of a severe beating. They held that she could order the medical personnel to discontinue nutrition and hydration of the patient. In that case Ellison sued Degreller and the nursing home where she was receiving nourishment and water through a gastrostomy tube that was surgically implanted into her stomach. She had breathed through a tracheotomy tube inserted into her throat, and she had been in that state for approximately 10 years. She had no significant possibility of improvement of her condition. The Kentucky court held that the mother could order that those treatments be discontinued in light of the medical finding that the patient's condition was irreversible. The Kentucky Supreme Court said in that case that: "We conclude the right to withdraw further medical treatment for a person when they are in a persistent vegetative state exists within the framework of the individual's right of self-determination and informed consent in obtaining medical treatment." They went on to say that: "We have recognized these rights to be exercised by an incompetent person through the process of surrogate decision making so long as the wishes of the patient are known." "The right determining medical treatment," they said, "is not a power that belongs to the judiciary. To grant or to withhold is not a power of the medical profession. It's a decision of the individual, "or in that case of the incompetent."

Within that framework, Kentucky then, its legislature, adopted legislation entitled Advance Directives and authorized the creation of a form declaring Advance Directives and in addition appointing a healthcare surrogate to make decisions. The legislature said that that form should contain an understanding that the document is only effective when the person who executed it no longer has decisional capacity has a terminal condition, or in a permanent unconscious state. The form shall have the option to designate healthcare surrogate and alternatives if they are necessary. And it authorizes or does not authorize either way that life prolonging treatment be withheld or withdrawn. Then it can authorize or not authorize the withholding or withdrawal of artificially provided nutrition or water. The document is to be signed and dated by the grantor and either witnessed by two witnesses or signed by a notary. If it's witnessed by two witnesses, those witnesses cannot be a blood relative, it cannot be an employee of a healthcare facility where that person is a patient, it cannot be an attending physician, nor can they be a person who is financially responsible for the grantor's healthcare. The legislature said that that document can be revoked in writing at any time and can be orally revoked at any time in the presence of two adults if one of them is the healthcare provider.

Kentucky law demands that the attending physician or healthcare facility comply with the wishes of the incompetent person, and if they refuse to comply with those Advance Directives the surrogate or the responsible party shall immediately be notified by the proper authority and be assisted in

finding a facility or a physician who will comply with the Advance Directives. The law is specific in stating that withholding or withdrawal of treatment of nutrition or water does not constitute suicide. The act does not condone or authorize the approval of mercy killing or euthanasia. It provides civil penalties for concealing or canceling of an Advance Directive, and it provides criminal penalties for falsifying or forging an Advance Directive or withholding knowledge of a revocation. In doing this the law provides immunity to the physician or to the healthcare facility freeing them from any liability for action taken in good faith on the existence or revocation of the declarations of a Living Will.

The most important part of that legislation is really the provision for the appointment of a healthcare surrogate. More than you're attempting to state what you want done, it's important that you name someone to make those decisions for you. They would make those decisions when you're unable to do so. But you have to inform those people what your wishes are. Talk about this with them. And it's also important that you let others know that you have made such a decision. You have to let your family know. If you have children and they are not present in this community, tell them. Tell all of your children that you have made such a decision, so that they're not caught by surprise at that time what your wishes are and what they think your wishes are.

Audience: Excuse me. In that case, I mean, like your Living Will, if you write it out in your Living Will and what your wishes are, you still need a surrogate.

Mr. Ruberg: Well, I'm saying it's best to have a surrogate because a surrogate knows what your wishes are and can see that that's done. There would be someone there to speak for you when you're unable to do so. And it would be very tough decisions to make. But with the consultation with the physician and with the people who are the chaplains, they can sit down and talk about what's a proper course of action, and they can make a determination and go forward and see that it's done on your behalf.

One of the things that's happened recently is that in April of this year, Pope John Paul came out with an article and a talk in defense of nutrition and hydration for patients in a persistent vegetative state, and that has generated a lot of debate back and forth. There seems to have been a presumption that nutrition and hydration are extraordinary means and can be withdrawn. The courts have held that. They say that they are medical conditions and can be taken away. The Pope did not say that. The Pope said that it is a treatment to help prolong life. But he did not say that you cannot discontinue nutrition and hydration. He indicated he wants to protect life. He said we have to rethink this process, that some people are a little too eager to discontinue and we need to rethink that.

There is no duty, however, to provide unending artificial nutrition and hydration for a permanently unconscious patient. Goods are for the good of the patient, of the person, and they only need to be continued if it can be shown that it's good for them. If it is an abandonment of a person, it is not an abandonment of a person to withhold artificial nutrition or hydration. It's an acceptance of a fact that that person has come to the end of his or her life, and they should not be impeded from taking the final step in dying.

The federal law on the Advance Directive requires that hospitals and healthcare institutions ask you when or if you are admitted to any hospital if you have an Advance Directive. They'll ask that each time you go to the hospital. They can make a copy of that and put that in your file. If you come back a week later, they don't know whether you revoked that or not, so they'll ask you again. If you have such an instrument that that's still your wish, then they'll put that in your file.

So it's important that you keep that Advance Directive in a place where it's available, where you know where it's at. Let your physician know that you have that Advance Directive. Tell your children or your friends that you have such a thing, that you have an Advance Directive. And discuss your wishes with your children and particularly with your healthcare surrogate so that they can do what it is that you desire.

If you have any questions to ask...

Audience: Did you say you do not have to start with IV's to keep them alive?

Mr. Ruberg: No. The idea....well...I think what you would end up with, if you could show that starting an IV would keep a person alive and improve their health or make them well, that would be necessary. If just putting an IV in or putting in nutrition and hydration would prolong death, that would not be necessary.

Robert C. Cetrulo: I want to introduce myself to the crowd. You [Mr. Ruberg] know me, of course. My name is Robert Cetrulo. I'm a lawyer in Covington, and I'm President of Northern Kentucky Right to Life, and I'm here to diametrically oppose what Mr. Ruberg has just said to you. The Pope did in fact say that withdrawing food and water would be euthanasia by omission. He said it is never permissible. He also decried the use of the phrase Mr. Ruberg used "persistent vegetative state." This is a dehumanizing phrase used by the pro-death community, and in fact never describes a human being. We are never vegetables, even the patient who is comatose. So he said that withdrawal of food and water is "euthanasia by omission," and I am quoting his phrase. And he said it is never permissible. Now there arrives a point in time where the body will reject water, and no one has ever insisted that it be given artificially at that point. But just to take a patient who is, as Mr. Ruberg described, in a persistent vegetative state but in reality is comatose, a human being who is comatose, and deprive them of food and water, then the deprivation of food and water becomes the cause of death, not the underlying disease. So he is wrong in what he said to you about the Pope.

Mr. Ruberg: And I think Mr. Cetrulo is wrong in what he is trying to infer what the Pope has said. The recent *Messenger* just on May 28, they had a whole article in there by this priest physician, and it's Fr. Miles Sheehan, who is Senior Associate Dean at Loyola University's College of Medicine. He said the Pope's statement meant Catholic institutions could not withdraw feeding tubes from people in a persistent vegetative state as long as the tubes serve their purpose of maintaining life. That's a distinction. If you're trying to maintain life and to make a quality of life better, you can do that. He does say the physician should look at each patient individually and decide in each case what will be helpful to that person. The Pope did not say that tubes had to be put in everybody. In cases

of the elderly who have reached the natural end of life and are dying, the use of feeding tubes should be decided on an individual basis with the wishes of the patient.

With all due respect to what Bob is saying, he and I disagree, and that is just a matter of people who have to study and read. I have read the Pope's decision from beginning to end, and I don't believe that he is saying what Bob is.

Mr Cetrulo: I think we ought to provide it to the people. I think it would be a great service, and I would be willing to reproduce it and send it out here. And you'll notice Mr. Ruberg added to the quote in the article to you have to provide the water as long as its purpose is to maintain life, and then he added his own phrase "and the quality of life." That is the problem, someone else making the judgment about quality of life. Food and water are not medical care; they are human care. And the Pope has spoken unmistakably and unambiguously that they may never be withdrawn.

There is a distinction to be made which is not made clear in the presentation you have heard here today between someone who is in what they call a persistent vegetative state and what we would call a prolonged coma. And, by the way, some of those people come out and survive. But there is distinction made between those patients and a patient who is actually in the dying process. In the actual dying process, no one insists that food and water needs to continue to be delivered artificially. But that is a matter of days. But to take patients who are simply comatose or in a persistent vegetative state, which you have heard Mr. Ruberg describe here, and deprive them of food and water is simply to starve them to death and cause death by dehydration, which I assure you, I could read you a painful decision which is in my book that I have written on this subject, that quotes a medical description of what it is to die from dehydration, and it's a very unpleasant description.

Mr. Ruberg: We're differing what the Pope has said. I've read his article. It's about seven or eight pages long. I've read it in *Omni*, a monthly publication that comes out. I think Bob's interpretation is different from mine. But you're welcome to read this. It would be great to do that. But I think you'll find that the majority of the people are of the opinion, not to mean they're right or wrong; but if you're doing this just to prolong death, you don't have to do that. And that girl in that nursing home in there for 10 years who is breathing through a respirator and a tracheotomy tube in her throat doesn't have the duty to continue life. That's not life. They took it out, and she died. They could have released her from that five years earlier. But, you know, we're talking about how could you tell when death is imminent. I don't know that a doctor can tell you that. He can tell me that he thinks that I'm going to die. They give their best and qualified opinion, and you go from there. I'm sure that when you make such a decision as a surrogate you would have to consult with the attending physician, consult with a chaplain at the hospital, and arrive at a decision that's in the best interest of the patient.

Mr. Cetrulo: But your last statement shifted gears back to respiration. I wasn't talking about a respirator at all. We know we're talking about food and water. So let's stay on that. Let's not talk about a respirator. I'm not insisting...

Mr. Ruberg: Breathing and eating...

Mr. Cetrulo: Well, the difference is that food and water is defined by the Pope and by historical Catholic theology as being ordinary care, not extraordinary, whereas a respirator is extraordinary simply for a time to determine if the patient can get back to normal breathing on their own. No one insists that that person be kept on the respirator forever. But when you take food and water away, then you are causing their death, and that is what the Pope clearly prohibits.

Mr. Ruberg: Well, I don't think that the Pope prohibits, I think the Pope is saying we have to rethink that, we've got to look at it more closely. You cannot just arbitrarily discontinue it, but that if it is such that it is not doing anything other than preventing someone from dying, that you have a right to withdraw it.

Mr. Cetrulo: What's preventing you and me from dying? Food and water is.

Mr. Ruberg: Well, I'm as close to death as any, I guess.

Mr. Cetrulo: It's preventing us from dying, food and water.

Mr. Ruberg: If death is imminent for me, then I can withdraw that.

Mr. Cetrulo: It depends on what you mean by imminent, you know, 'cause that's a phrase that's widely used.

Mr. Ruberg: _____ saying, though.

Mr. Cetrulo: Unless you're in the dying process, food and water, the Holy Father has said clearly, must be provided. That's Catholic teaching.

Mr. Ruberg: I agree with that. I'm not arguing that food and water is not helping the body to survive. But when the body begins to die, it rejects food, it rejects water. When a person dies without anybody helping them, with no tubes in at all, they'll quit drinking, they'll quit eating. Just to do that by inserting a tube in the stomach is wrong at that point. You're not letting them die.

Mr. Cetrulo: How about giving them then food and water by mouth. Is it artificial when someone has to spoon feed them with water, is that artificial?

Mr. Ruberg: No.

Mr. Cetrulo: Why?

Mr. Ruberg: It's artificial if you're putting it in in a tube in the stomach. The body is not doing that. You're doing it artificially.

Mr. Cetrulo: Yeah, but why isn't it artificial then for a nurse to put it in your mouth by when you can't take the glass yourself?

Mr. Ruberg: Well, I'm not going to argue semantics, Bob. I really think that you and I differ substantially, and I respect your opinion. I don't think you're saying what the Pope said.

Mr. Cetrulo: We'll get the written document and let the people interpret it.

Mr. Ruberg: I've read it myself.

Audience: May I ask about this case that was in Florida not too long ago where the woman was being fed for 13 years, and her husband asked for it to be withdrawn and her parents reneged against that and started her all over again. I mean...

Mr. Ruberg: Very emotional case.

Audience: How many years is there, length in time...

Mr. Ruberg: It's not time. It's the deciding factor. It's the decision as to whether you're extending life or whether you're trying to extend death.

Mr. Cetrulo: By the way, the Schiavo case you're speaking about, Terri Schiavo, contrary to what is generally written in the secular press, if you read some Catholic journals you'll find that she was cognitive. She responded to people who come in there. She blinks her eyes. She shows cognition, and she is not dying. She's simply comatose. She's not dying. She will die if her husband, who by the way is beneficiary of a large trust fund that she has, has his way and kills her through depriving her of water. The parents said take the money and just give us our daughter, and he won't do it. He's living with a woman out of wedlock and has two children by her. So these are the unseemly facts that creep into the reality of this whole death and dying controversy. People who have an ulterior motive frequently get involved. The patient should not be killed in a terrible way by deprivation of water when they're not dying. Terri Schiavo is not dying. She's a perfect example of what the Holy Father said. You don't call people vegetables. And so long as they're alive you continue to give them food and water, mandated by moral law. That's what the Holy Father said.

Mr. Ruberg: But he does not say that you have to keep somebody alive if you're just preventing death. That's a natural thing that the body does is die. And what I hear is that they're talking about...once you start it, you just go on ad nauseam, that's not so.

Mr. Cetrulo: Well, you say preventing death. You know, back to what I said. Our death is prevented by our nutrition. And so is Terri Schiavo's death prevented by her nutrition. Now if you're talking about a terminal cancer patient or a terminal heart patient who literally is hours away from dying, that's one matter. If you're talking about a person who simply is comatose, as is the Schiavo case, which your initial remarks covered and said that the Pope said you don't have to ever

do this, that's wrong. He said you do have to do it. He said you do. And it's logical that what causes the death in that instance is not a disease. This lady has some brain injury. Whether she'll recover or go back to where she was before, nobody knows. Some people do, some people don't. But the answer is, we don't kill her by taking away food and water. The brain disease is not going to kill her. She's not dying. She's not dying. She will die if we take the food and...

Mr. Ruberg: It's isn't whether dying or not dying...

Mr. Cetrulo: Well, you need to read the record.

Mr. Ruberg: A physician could make that kind of a judgment and decision. You and I couldn't tell if a person is dying.

Mr. Cetrulo: We've read that argument in the abortion issue. Let's not leave these decisions up to physicians. We've seen the caprice they're capable of.

Mr. Ruberg: I appreciate that, but be that as it may, we have a wide difference of opinion.

Mr. Cetrulo: Yes.

Mr. Ruberg: Yes, Bob.

Audience: What about Living Wills now?

Mr. Ruberg: I think that Living Wills are the same as they were before.

Audience: How good?

Mr. Ruberg: They're good.

Mr. Cetrulo: You can have a Living Will. You should have a Pro-Life Living Will that spells out that you should never be deprived of food and water, and you should be given whatever medical care is appropriate to your condition. That's what you should have to protect yourself.

Audience: _____ no extraordinary means. I mean, that's what your Living Will says.

Mr. Cetrulo: That's what it says. And if that's all it says, then you are very much in danger of being knocked off by being dehydrated unless you have a provision in there that I shall be given all medical care appropriate to my condition and that this always includes food and water. That's what you should have in there, a Pro-Life Living Will.

Mr. Ruberg: You should make sure that your healthcare surrogate knows what your decision is and what you wish. That's very important.

Mr. Cetrulo: But then if you haven't given them guidelines in the document, then they're free do to what they want, and it depends on what their interest is.

Audience: There are people dying every day. Have you heard any other problems of people dying, that they should be doing something and are letting them die?

Mr. Cetrulo: Father, I can tell you a number of cases where I've had situations where children have come into my office from a divided family where the other children have lost the faith, and the doctor at St. Elizabeth Hospital wouldn't talk to my lady who wanted to continue the woman to have food and water. Yes, there are situations where people are caused to die illegally and immorally in our own community right now and all over the world, it's happening, before their time.

Audience: _____ situation?

Mr. Ruberg: Bob and I won't settle this today. I'm sure we never will. We never have. It's something you'll have to look at and give judgment as best you can and consult if your priest if you think there's a problem. I wouldn't consult with Right to Life, I think they're political; but that's up to them. And I'd rather talk to a priest to get better ideas.

Audience: What about the expense of continuing this? It used to be an extraordinary expense would be a reason for stopping something. What about today? Who pays when you keep somebody going?

Mr. Cetrulo: Well, if we put a cost of benefit analysis on human life, Father, that's what drove Roe v. Wade. That's what drove Nazi Germany. If we view ourselves simply as dollar fodder. The answer is we don't have a right to kill people for whatever consideration. And killing people is what is involved when you take away food and water, precisely. The Schiavo case, the persistent comatose patient – they're not dying, Father. They're not dying. But they will die if we starve them.

Audience: But I have to say, who pays for this?

Mr. Cetrulo: I'm saying to you that that's really an irrelevant question, because then that buys into the whole mentality of a cost benefit analysis of human life.

Audience: I know there are two points there. But the point is, somebody has to pay. That's the way the world looks at it now.

Mr. Cetrulo: A lot of people in the world do, which the Holy Father recognizes as a great risk, and therefore he's defined the definitive point, which is you don't take away food and water from a patient who is not dying. That's what he said.

Audience: Yeah, I know.

Mr. Ruberg: Thank you. I enjoyed being here with you, and I appreciate your attentiveness, and look forward to seeing you all some other time. Have a good day.

Audience: I think my Living Will should be okay, don't you?

Mr. Ruberg: I do. Yes, mame. You can talk to him about that.

Audience: I will.