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From Death into Life: Catholic Teachings on End of Life Decisions Wednesday, February 11, 2015 9:15 AM COR Center Morning Enrichment, SMMP

So as much as possible, **we need to think about and anticipate our own death.** In a way, we have to plan our own death so that it doesn't catch us unawares, which it often does.

Now the fact is that modern medicine has produced many, what people might even call, miracles, but these miracles are both good and bad. There is a good and a bad side to this modern medicine. **Beyond doing the normal, natural things we do to keep people alive, what sort of responsibility do we have for extraordinary means, and what are extraordinary means?** That is really the question put before people today. There is no hard and fast answer, and that's very important for us to keep in mind. Some people look to the Church for black and white answers for issues. Well, the problem is the issues are constantly shifting, and that's why St. Thomas talks about the virtue of prudence. **Prudence knows when to apply what principle to what and to whom.**

So in regard to some of the modern methods of healthcare, for example, take **a breathing machine.** Is anyone ever obliged to use a breathing machine, which is an extraordinary thing? Well, yes, sometimes. For example, a man who is 40 years old and has three children who has double pneumonia is most certainly obliged to try the breathing machine so he can recover so he can be there for his children and his wife, naturally. That is an obligation. A person in fourth stage lung cancer is not obliged to use the breathing machine. It is permitted if that in fact would alleviate his or her suffering, but it's very possible the breathing machine would, in fact, enhance his or her suffering. And all this has to be taken into consideration, and it's not simple. **It's very complex. And it differs from person to person.** Again, if a man **49 years old has leukemia and there is a chemotherapy available that is effective 85 % of the time** in this particular kind of leukemia, **one would think that that person has an obligation to try that therapy.** It's only 85 % successful; it may not be successful. It may cause pain and suffering. But if the overwhelming probability is it would be successful and he could overcome his leukemia because it is after all very often curable, one would think and our principles would indicate that that person most likely should take that chemotherapy. However, if in the same situation there was **a chemotherapy that was only 30 % successful, that's a very different kind of question.** And that's what we have to keep in mind.

My mother had a cancer in her abdomen and it was not treatable by any known method. The doctor said, "I'm sorry, but there is nothing that we know that will help you. There is **an experimental drug**, but we are not recommending it. My mother said, "I'm taking it anyway." And she did. She was 63 years old. She thought she had a long life ahead of her. Well, this experimental drug, in fact, was successful. And not only that, but they warned her of possibly very severe side effects, but in fact there weren't any—lucky for her. But another person could have had terrible side effects and it would have been a failure. Is that knowable ahead of time? No, this is the problem. We don't know ahead of time whether this will work or won't. So are we obliged to do it? No, **we are not obliged to do it if we don't know what the effects are.** If something is experimental, **we are never obliged to do something experimental. We are obliged to take normal means and even extraordinary means if**

there is high likelihood they will work and under conditions that a person is capable of further life. So as I said, a 40 year old man, a 30 year old woman, yes, they have an obligation to even use more extraordinary means. As I say, it's a sliding scale what's extraordinary and what isn't, because they have more life ahead of them. But a 95 year old person does not have the same responsibility whatsoever.

So we have to realize that eventually we shall die and we need to die with dignity and we need to die surrounded with friends. That doesn't mean at the moment of death, because people often want to die alone—that's okay. But along the way they should have friends. They should have family. They should be cared for. So that's what we want to do. We want to produce a culture of caring for the dying, giving respect to everyone, but not trying to resist death beyond what is reasonable. So that's the general framework. I hope you understand so far.

In Catholic healthcare it is often stressed, as I mentioned to a few of you who came in later, that it is very important for **healing of relationships in the dying. So that's part of it. It isn't simply physical—it's emotional and spiritual.**

So let's list some basic principles. First of all, **in Catholic thinking we are not owners of our lives.** We don't own our lives. We don't own anything. **We are only stewards.** We are stewards of our lives. We are stewards of our possessions, so to speak. We are not masters. Christ is the master; we have to keep that in mind.

Everyone needs, whether sick or well, **everyone needs appropriate food and water. Everyone needs pain control, bed rest, suitable room temperature**. This is all obvious, **and basic caregiving. These are not considered medical treatments.** These are just basically what people need. **We need symptom management.** But we also need, **people need, compassion.** Compassion is not necessarily what you get from the medical establishment. So this is something. The questions we talk about go way beyond what you get in healthcare or from healthcare facilities. **People need acceptance, love, and care on every level.** But moreover as **from the Catholic viewpoint we look at death as the gateway to eternal life**, and so it really is something we should learn to welcome and to await. As it says in the Creed: "And I await the resurrection of the dead," we look forward to the resurrection of the dead. **We don't try to oppose it or put it off as long as possible.**

What are some of the things that we mustn't do? Well, **we mustn't ever hasten death or actually positively cause death.** Some people do this out of a sense of compassion and it's called euthanasia. **Euthanasia has two kinds. One is active when you actually cause someone to die; the other is passive where you withdraw from someone something fundamental that they need to live by and you don't let them have it.** In other words, you starve them to death. This is not acceptable. Now **there does come a point in the process of dying where you can no longer take water in or food, nourishment; your body doesn't metabolize anymore.** Then it is torturing them, torturing a person, to put food into them. At a point you must hold back. **That is a point really within a few days of death. So we have to learn how to judge that.**

Sometimes people judge the quality of life by standards that are very false and artificial. So something else we should keep in mind and try to avoid is judging the standard of life and saying, well, that life isn't worth living. Well, **who are you to say it is worth living? What makes life worth living?** So these are really questions we have to raise, not necessarily have to answer. But we must never deliberately cause someone to die and we must never withhold something basic, a basic need which I already mentioned. **Nor must we ever kill ourselves**, causing ourselves to die either positively or by simply withdrawing life from ourselves, with, again, the caveat that **eventually we cannot eat anymore. Eventually even hydration is painful.**

Some people bring up the issue of the **Permanent Vegetative State**, so to speak, where a person is still alive in the brain stem, but the rest of the brain is gone. **Technically that person is not dying, so we really need to hydrate them and to feed them as much as possible.** However, there are cases when this becomes burdensome. So even ordinary means and small extraordinary means can become overly burdensome for the patient him or herself; in other words it causes tremendous anxiety; it causes too much pain, and that's not always the case, but sometimes it is the case, well, then you don't want to cause that. That's torturing them. You don't torture people to keep them alive. But ordinarily you give food and nourishment to a person who is in a permanent vegetative state, so to speak—that's a very poor term actually—**until they get to such a point where their body will shut down, which it will eventually, as all of our bodies will eventually.**

Now a person in that state, would we have to provide a breathing machine? Well, no, no, that would be extraordinary for that situation because there is no hope that a breathing machine will bring them back to a healthy life. **So you have to ask yourself: What is the hope? What kind of hope do you have? What might happen if we use this means? What does it cost to us in terms of pain and expense? "Us" meaning both the family and the individual himself or herself.** Those are all issues that have to be taken into consideration. It could be that something relatively minor and seems to be not a great expense, nevertheless, is very burdensome for that individual, and that individual just can't tolerate it, so then you must eliminate it. If in so doing, death comes, that's not what was desired. What was desired was to comfort the person and not impose on them. **Sometimes we end up with what is called double effect: you want one thing, another thing results. Life is that way. Life is complex; it's not simple.**

The bishops of New York have written this little statement on extraordinary and ordinary means. I will read it. I think it is good to hear this.

"The immorality of directly intending and bringing about our own death or of assisting in the death of another by intentional action is evident enough. Decisions can become much more complex and more difficult—when we contemplate the removal or withholding of medical treatment such as a ventilator or dialysis. In an age of rapidly advancing life-sustaining treatment technologies, such decisions are not infrequent.

Out of deep respect for the gift of life, **we must always accept, and others must provide, ordinary medical means of preserving life.** Ordinary means are those that offer us a reasonable hope of benefit and would not entail excessive burden"—so reasonable, what is

ordinary? It is reasonable hope of benefit. That's very important. What is a reasonable hope of benefit and to whom? The U.S. bishops say, well, to whom is to the person, not to the doctor. And the person has to reach this conclusion after talking to doctors and perhaps priests or/and counselors. So it's not a simple decision. It has to be an informed decision. So **"reasonable hope of benefit and would not entail excessive burden"** on that person, and that is relative to different people. Some people have a very high pain threshold, like my father. My father had hammer-toe surgery and he said he didn't feel any pain. The doctor gave him all kinds of pain pills. "What's that for?" "Well, that's for the pain you are going to have in your foot." He said, "Nah, I didn't have any pain." He has been that way his whole life. That's just kind of unusual. But actually a lot of people do have high pain tolerance; other people don't. Some people have no pain tolerance. This all makes the word "burdensome" relevant and relative—both. It's on the person, but also the family and the community. **No one is obliged to bankrupt his or her family in order to bring about an extension of life.**

So this gets down to then, well, what does health insurance provide? Well, that is all based on probabilities and cost. So there are some rare diseases where the health service will not provide healthcare because of the probabilities involved and because of the cost involved. So what are you to do? Well sometimes there is no solution and that's the answer—you can't.

"Ordinary means of medical treatment are morally obligatory"—understanding all those contexts I mentioned. "Withholding ordinary care with the intention of causing death"—with the intention of causing death—"is considered passive euthanasia and is always gravely contrary to God's will."

Then they go on. **"But Catholics are not morally bound to prolong the dying process by using every medical treatment available."** Some people actually think this way. And one of the problems is that some health providers, like for example the 911 service, they have a protocol where if someone is passed out, they are supposed to revive the person. Well, what if that person doesn't want to be revived? What if I know that person doesn't want to be revived and I have power of attorney? It doesn't matter. As I stand there and say, "Oh, I have power of attorney and I know that he doesn't want to be revived because he is very sick." They will say, "I'm sorry, but we have to do this. Somebody called us; we are here; now we have to do this; it's our protocol." They can only be stopped by a doctor. Now there is something, **POLST**, Physicians' Order for Life Sustaining Treatment, so if you have that, that is effective, and they will listen to that because they do take orders from doctors. But that's the thing about—**doctors are supposed to take orders from the patient, but other practitioners take orders from the doctors.** This is our healthcare system—it's our healthcare system. So we have to keep that in mind.

So that's why my friend, Sonja, for example, when she had terminal cancer—and she had it for years, she lasted years beyond what the doctor said she would—she took no chemotherapy; that's why she lasted so long. It's true. Sometimes chemotherapy shortens your life; it can. Well, anyway she didn't take it, but she lingered and lingered. She needed all this drug therapy for pain. She needed a lot of that, and she got it. But **one of the things they put on her refrigerator was an order not to resuscitate.** Should she collapse, she

didn't want anyone to revive her, naturally. She had nothing to look forward to but a slow, painful death. So that's why these orders not to resuscitate are important.

Question: If she is in a facility and someone calls an ambulance, they would have to resuscitate her? Yes.

*Barbara Burkhardt: Not if she had the POLST.

Father Paul: Not if she had the POLST.

Barbara: If she is in an assisted care facility, they will have that.

Father Paul: But what if you are at home?

Barbara: If you are at home, they recommend that you put it on your refrigerator. It's like bright pink!

Father Paul: The physician has to sign it.

"Some treatments may be considered extraordinary (as opposed to ordinary) and are not morally obligatory because the burdens and consequences are out of proportion to the beneficial results anticipated." So those are a lot of words; let's unpack that for a minute. So the benefits—the burdens and consequences are out of proportion to the benefits anticipated. So what are the benefits anticipated, and who is anticipating them? See, you could anticipate benefits that are completely unreasonable. So you have to start to understand really and **you really have to be informed.** And in formation you have to ask the questions. You can't just go to the doctor and say, "Well, what can you do for me?" That's not the right question. They will tell you. But I will tell you something, when the doctor has that same problem, the question is: **"What would you do if you were me?"** That's the question to ask, not "What can you do for me?" because the truth is there are many conditions when a doctor gets it, they just go home. They shut their office, say good-bye to everybody, and they go home. They don't go to the hospital. They don't go see another doctor. They know this very well, the results anticipated and the benefits anticipated, they know they are out of proportion to the burdens and consequences. They know that. They know it's not worth it. It doesn't mean that there is no chance at all. There could be, but it isn't worth it. They have seen it; they have watched people. **There are many treatments available that just prolong suffering. That is not obligatory; in fact it isn't even Christian.** I had a discussion once. I was at dinner with this lady and her husband. The lady said to me, "Oh, I wouldn't want every single thing possible to be done to keep me alive. I just wouldn't want it." And her husband said, "Oh, I would." And I said, "Really, would you really want everything possible done to keep you alive?" "Absolutely." That is frankly crazy. Again, ask the right question. Not: What can you do for me? but "What would you do if you had my problem?" So you have to be informed.

So sometimes we have a cancer patient and a very aggressive or expensive treatment. **If it's a low survival rate, it's actually foolish to burden yourself with it. "Our Church suggests that when making a decision to accept or refuse treatment, we should take into consideration," number one, "the type of treatment recommended**"—and by whom it's

recommended. In other words, does the doctor say, "That's what I would do if I had your problem"? Or is that just "Well I recommend that because that's what we say around here," or "because that's what is available and I'm paid to do this"? Those are two different questions.

Secondly, "how risky or complicated it is?" Three, its "cost," and to whom. You know, just because something cost the insurance company doesn't mean that it's free. Some people say—I've heard this; people have actually said this: "Oh well, it doesn't matter; the insurance will pay for it." A friend of mine, a dear friend of mine, said that to me about several things. "Well, it doesn't matter because the insurance will pay for it." That's not the point. **If it's not worth anything, it doesn't matter if the insurance company pays for it.**

"Side effects"—big issue. And unfortunately that's not foreseeable in many cases. Again, my mother had this very supposedly radical chemotherapy and she didn't have side effects, but other people have with that same treatment.

"How painful" will it be? You are not obliged in order to save your life to endure pain for a long period of time. A short period of pain, yes, especially if you are younger. At the end of your life, if you are in your 90's or late 80's, you are not obliged to endure pain in order to stay alive. But if you are young, well maybe you should endure a little pain if there is a good chance that you are going to survive. And then there is the other issue of **what's available to everybody; there is a common good issue.**

"One of the most important moral distinctions for end-of-life decision making is between what is morally obligatory and what is morally optional. Even if death is thought imminent, ordinary care owed to a sick person cannot be legitimately interrupted. On the other hand, discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to the expected outcome can be legitimate." So I think we have said enough about that. Does anyone have any questions on this topic?

Question: What is morally obligatory? **Morally obligatory means you are obliged to do it morally.** "As a patient?" Yes. "I always think of the family." Well, you see the family is supposed to—this is what the bishops say in this other directive—the family is supposed to do what the patient has already prescribed. Now what if the patient hasn't prescribed anything? Then you have a problem.

*Question: Are you going to talk about advanced directives? Yes, do you want to say something? You know more about it than I do.

Barbara: In healthcare there is a form that we all really have a moral obligation to fill out. And it's called **"A Medical Power of Attorney for Healthcare."** In that document you are stating what your wishes are. And you are saying that you want everything done, no matter what, which some people do make that choice. Or you are going to say what makes sense: that's the burden of treatment to the benefits, so that's the weighing what makes sense. **When you have filled that document out and you have that conversation with your family, when something happens it makes it so much easier for your family, because they know what you said you wanted.**

Question: Does it actually say, “what makes sense”?

Barbara: No, this is a form you can download from the state of Illinois’ web site. There are three options. The first option is the one that Father was talking about, **if the burden of treatment outweighs the benefit, then you don’t want it done. That’s option number one. Option number two states that if my doctor feels that I’m not going to wake up and it doesn’t make sense anymore, then I don’t want any further treatment. The third option says no matter what, I want everything done.**

Father Paul: And I doubt that is actually very moral from a Christian viewpoint, the third one. That’s like my friend at the dinner table who said he wanted anything done that was possible.

Question: Can you get that form any way other than a computer?

Barbara: If you want those forms, I can certainly put them in the office.

Father Paul: That only comes into effect when you cannot do it yourself. What you should also say, though, on that form is that **just as if you were still able to decide, you would have to consult with doctors and let’s say priests or moral authorities, so should your designated person.** I would advise against saying something blanket—like under no case would I go on a lung machine. What if it was for twenty hours, and then after that you would be fine? I wouldn’t want to bind my attorney with that sort of limitation, myself, and I don’t think it would be exactly a terribly good idea morally either.

Morally optional means that it’s neutral; you could or not do it—either way. You would not be committing a sin by doing it, but you wouldn’t be committing a sin by not doing it—morally neutral.

Barbara: **So when you sign the Durable Power of Attorney it’s a two-sided document. One side is where you are naming the person that’s going to make the decision.** That’s really all you have to do. **The back side is saying this is what I want.** So **the person is obliged to follow through with your wishes, and if they disregard what you have written on that medical power of attorney, then it can go to an ethics conference.**

Father Paul: “Power of Attorney” means they have a power like an attorney for healthcare.

If you have two homes you have to have two sets.

Barbara: So on this form you are naming your primary, one person, which can be really hard for people that have three or five kids, **you name one person, and that person is through the decision is made. Then you can name backups.**

Father Paul: Now getting a little more deeply into issues, one of the issues that people face when they are dying is fear, **fear of dying.** And this is, again, something that we can anticipate and deal with, that we are mortal creatures, and we are going to die, and we need to face that so when our time come, in a way, we have dealt with this. So dying is not

something which is an evil thing. **It's our exit from this world and our entrance into the eternal life.** So we have to keep that in mind. **Very often people will need some sort of ministry, some sort of pastoral care, in regard to the fear of dying.** And if you have people at home, I think you need to think of that.

Also there is a **fear of abandonment** that often people experience. These are irrational, but they are part of what people often experience when they are dying.

Now **I think the best place to die is probably at home**, but when you die at home you are also putting a burden on your family, so it's good if you can do it, if the family can do it. Hospice is at home or in a hospice place. That is probably much better than somewhere else. That will involve this awareness of these fears of dying and **fear of pain as opposed to pain itself**, fear of loneliness and abandonment.

Poorly managed pain is also one of the problems that people often complain about. Now hospice is really one of the better ways to deal with managing pain. Many people in hospitals have actually complained that their pain isn't managed at all. Why is this? Well, I really don't know and I'm not in a position to say. But apparently many doctors are really thinking about giving treatment, not caring for people's pain; and those are two different things.

Barbara: Well, that's where palliative care comes in. People are often afraid of hospice because that means you are dying, but **palliative care is about making you comfortable**, and that's the primary purpose of palliative care. **In order to engage hospice you have to have a diagnosis of a terminal illness.** People that are suffering great pain don't always have that terminal diagnosis. And **you can get in and out of hospice**—absolutely. Six months is typical.

Father Paul: Now my friend Sonja was in hospice for much longer than six months, but she had an unusual case.

The other thing is **while you are in hospice you cannot go to the hospital and have surgery.** That's the requirement of hospice that you don't try to advance through medical procedures your life; **you are accepting that you are terminal.** You can leave hospice, but you can't have both together.

Question: How do you engage palliative care?

Barbara: **So when you are in the hospital and you are suffering, you are in a lot of pain, you can request palliative care.** If you have a palliative care physician, that would be one of the doctors on your team and they would confer with you.

Father Paul: I want to ask you some questions for you to talk about, but before I do I thought it might be good to mention some **terminology** (from some notes on the publication by the USCCB.)

Death with Dignity. "Within the Catholic perspective, death with dignity is death that is not 'unduly burdened' by clinical environment and medical technology required to prolong

life. Life-sustaining interventions are used only to allow the patient to live with dignity. When this is no longer possible, patients, family members, and caregivers are freed from obligations to prolong life at all costs and every situation. Death with dignity should not be equated with the right to die.

Right to Die. Strictly speaking, there is no such thing as an absolute right to die either in Catholic moral tradition or in U.S. legal tradition. From the Catholic prospective, the autonomy and self-determination of the individual are always weighed against one's responsibility toward God and others. In its recent ruling in the case of Nancy Cruzan, the U.S. Supreme Court balanced the individual's "liberty interest" in refusing unwanted medical treatment against the state's interest in preserving life. In many circumstances, the term "right to die" is used to denote an individual's right to refuse or withdraw life-sustaining treatment within the limits provided by law and moral teaching, a position which Catholic moral tradition strongly supports.

Permanent Unconsciousness; Persistent Vegetative State. An individual is said to be in a persistent vegetative state or permanently unconsciousness when the cerebral hemispheres of the brain (which control consciousness, awareness, and other voluntary and involuntary actions) have ceased to function, while the brain stem (which controls respiration and more primitive reflex behavior) remains unimpaired. Individuals in a persistent vegetative state go through periods of both wakefulness and sleep and may exhibit spontaneous, involuntary reactions to certain external stimuli, such as light and sudden movement. They are, however, incapable of any conscious awareness of or voluntary response to their environment. Such conditions are generally regarded as irreversible. Most physicians regard the rare case of a patient "waking up" from a persistent vegetative state as evidence of an incorrect initial diagnosis. In contrast, coma is a state of unconsciousness in which a person does not have sleep-wake cycles and exhibits no voluntary reactions or responses. The person in a coma appears to be asleep."

So those are some perhaps helpful definitions.

Response to a Question: A person in a permanent vegetative state does eventually die. That can be measured when they can no longer metabolize food and they cannot take water anymore; they start to bloat. You can tell. I don't know how long it takes. Some people last quite a while in that state; it's kind of sad. But, again, now the issue comes back even ordinary care, when does that become excessively burdensome. So that all has to be weighed together. **No one person can decide all that by himself or herself. That's why we are having this talk. You need help making decisions, medical and moral help.**

Now homework time:

What were your earliest experiences of death and dying, most recent experience of death and dying?

If you were truly able to plan your own death (age, setting, disease, people around you, etc.), what would be your most preferable death, least preferable death?

What do you fear most about death—the dying or the death?

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