

Chaplain – Robert Baral

Location – Neurology Intensive Care Unit

Patient – XY, 80+ year old married male

Days in hospital – 3; Length of visit – 45 minutes

Religion – Protestant

Theme: The Withdrawal of Futile Extra-Ordinary Care at End of Life:

Not Euthanasia, But The Gift of Palliative Care

## **I. DATA**

The patient is an 80+ year old male, admitted 3 days ago with a catastrophic stroke. He is now unresponsive on ventilator with very poor prognosis and little likelihood of recovery. He had two ministrokes last several years, diabetes, heart failure and has been deteriorating recently. Mr. Y was having dinner at home with his wife, when he slumped over unconscious. Paramedics found the patient unresponsive, with dangerously elevated blood pressure, slow heartbeat and with no response to pain.

The patient and his wife have been married for 50+ years. They have one daughter locally and two sons out-of-State. Wife describes them as very supportive. Successive brain scans show a progressing critical brain injury. Doctors have advised Mrs. Y that the patient is not likely to wake up. The wife is dealing with decision to withdraw her husband from the ventilator, which is virtually certain to be followed by clinical death. She is torn between fear for him of an unacceptably poor quality of life and suffering if ventilator support continues versus feelings of misplaced guilt if she chooses to withdraw ventilator support.

## **II. PLANS FOR THE VISIT**

I am sitting at Nurse's desk in Neurology ICU charting a note on a computer for a patient who has died in the next room. An older lady approaches me. I introduce myself as a hospital Chaplain. She tells me she is the wife of the patient in the ICU and needs to talk to me now. I reply that I would be happy to talk to her. She asks me to join her at her husband's bedside. I say a silent prayer, "LORD, make me an instrument of Thy peace."<sup>1</sup> I join her at the bedside. I knew this would be a difficult case.

## **III. OBSERVATIONS UPON ENTERING THE ROOM**

The room seems dark to me. The patient is on a ventilator, the head of his bed elevated slightly. I do not see any personal items in the room. There is the usual small forest of intravenous pumps and lines. The wife sits down on a chair. She is crying quietly on and off, wiping her eyes and nose. She asks me to sit down on the other chair.

I sit facing her on my left and facing her husband, Mr. Y. For a few moments the only sounds I hear are a beeping intravenous pumps and the ventilator chugging away. A Nurse passes through silently to attend to an intravenous pump. I sit a few moments with the wife quietly. Her tears subside and she is able to speak.

## **IV. INTERVIEW**

W – wife; C – Chaplain

C1 – Hello, Mrs. Y. May I come in? [I knock. I have been invited in by the wife, but I always ask permission to visit.]

W1 – Come in please! [Wife jumps up from chair. Wife is crying.]

C2 – [I walk directly over to wife. I offer my hand and she places her hand in mine. I hold her hand and place my other hand on top of hers. Immediate solid eye contact.] Thank you for asking me to be with you and your husband. May I also say hello to your husband?

W2 – [Wife nods yes.]

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<sup>1</sup> 1, Saint Francis of Assisi, "Peace Prayer." National Shrine of Saint Francis of Assisi, San Francisco, California, USA. <http://www.shrinesf.org/franciscan-prayer.html>.

C3 – Hello, Mr. Y. I am Bob, one of the hospital Chaplains. I am going to visit with you and your wife for a while. [Patient makes no response. I always presume that patients are aware and can hear, even if they are not apparently conscious. This also affirms the humanity and dignity of patients in the presence of their loved ones. ]

C4 – [I turn to the wife.] May I sit down here with you, Mrs. Y?

W3 – [Wife sits down again. I follow suit. She is wiping her eyes. Period of silence as wife's crying subsides.]

C5 – Can you share with me what happened to your husband?

W4 – He had a stroke. He's not opening his eyes. He's comatose. And it's not going to change.

C6 – I see. Your husband had a stroke and he is not waking up at all. [I nod my head slowly up and down. I lean forward slightly.]

W5 – It's hard for me to take away his oxygen. I feel guilty, but we don't want him to pine away in a nursing home. Is that murder? Please tell me what to do!

C7 – [I am taken aback at how open and freely this lady shares with me. I really am the person she needed right now after all! Mental note. Alarm bells. LORD, help me to tread carefully!] So you are struggling with feelings of guilt for wanting to take your husband off the ventilator. But you are also fearful that, if you don't, he might pine away in a nursing home for a long time. And you are wrestling with the question that, if you do take him off the life support, and he dies, is that murder?

W6 – Yes. [Wife begins crying again on and off.]

C8 – [I give a few moments of silence.] May I ask you some questions, which will help me understand what you are going through a little more?

W7 – Yes.

C9 – Have you and your husband and family talked about these kind of things before?

W8 – Yes. He had two ministrokes. And he didn't want to be kept alive if he became like this.

C11 – So you and your husband have already talked about this kind of a situation, that if he became unresponsive and there was no hope of him waking up, that you both would not want him to be kept alive with advanced care. Is that correct?

W9 – Yes.

C12 – And are you having to make this decision for your husband alone, or are there other family members that you are sharing these burdens with?

W10 – We have a daughter and she will be here this evening. We have two sons [out-of-State] that call me a lot. They will be here tomorrow.

C13 – And do you all agree on what you would do for your husband in this situation?

W11 – Yes. We don't want him to pine away in a nursing home.

C14 – And do you have any support from a Faith community?

W12 – Yes. We live at a local retirement home. We have Reverend A there as our Chaplain.

C15 – And does Reverend A know that you and your husband are here? Have you talked to him?

W13 – No. He is so busy. [Wife explains that she didn't want to make a bother of herself to their Pastor.]

C16 – And is this decision that you feel pressing on you something that you need to make right now, alone?

W14 – No. Not right this moment.

C17 – And so the question you are asking yourself and GOD is, if you take your husband off of the ventilator, is this what he would want? And is it murder? And are these feelings of guilt matching what you and your family have, it sounds like, already decided on? And is it okay to ask our Pastor for support?

W18 – I don't know. Would this be taking his life? Can you tell me what to do?

C18 – As a Chaplain, I can't tell you if you should or shouldn't take your husband off the ventilator. But from my Faith Tradition, I can tell you the Catechism of The Catholic Church clearly says it's okay to withdraw or withhold "extra-ordinary care," especially when there's no reasonable chance of recovery. It's not causing death to remove the ventilator in this situation. It's simply accepting the inevitable outcome and refocusing on making sure your husband is comfortable.

W19 – So it's not murder to take him off the ventilator! I'm so relieved to hear you say that!

C19 – No, not in any way. This is very important for you to understand and have peace over. The Catechism calls "comfort care" a "gift of disinterested charity" at end of life, where death is not willed to be caused, but acknowledged as an inevitable end. It's not "euthanasia," but rather "palliative care" – to maintain dignity, reduce suffering and maximize quality of life & comfort at end of life."

W20 – We all already agreed on what to do if this should happen. Now I know it's okay to make that choice.

C20 – Yes, Mrs. Y, it's okay to make that choice, if that is what you all decide.

W21 – Our children will be here tomorrow.

C21 – So you don't need to make that decision by yourself alone today. You can make it with your family around both of you. And I think it would be very appropriate to ask Pastor A to be with you tomorrow as well. GOD gives us Pastors for times like these.

W22 – I can call him and ask for him to be with us.

C22 – And one of us, the hospital Chaplains, can be with you all tomorrow – if you want - if your Pastor can't be with you. [Almost on cue, the Doctor comes in. I remain and listen with the wife's okay. The wife asks the same questions and the Doctor responds very honestly and caringly with the same explanations. He shares the very poor prognosis and the highly unlikely possibility that the patient might ever become conscious, much less become functional. He affirms to the wife okay to wait until their children arrive tomorrow before making the final decision about removing the life support.]

C23 – [After the Doctor leaves, we resume the conversation.] So the Doctor suggests you and your family wait one more day before making this decision so you can all be together. So you don't need to make this decision right now when you are alone.

W23 – So we'll wait one more day. My daughter and sons will be here tomorrow and I'll invite our Pastor, too. Would you say a prayer, Chaplain Bob?

C24 – Certainly. [I read a Scripture and I pray with Mrs. Y. I pray for GOD's guidance and strength for family, for comfort and peace for the patient. I affirmed the love Mr. & Mrs. Y have for GOD, each other, their children and generations yet to come:

### **I JOHN 4:10-16**

<sup>10</sup> In this is love: not that we have loved GOD, but that He loved us and sent His Son as expiation for our sins.

<sup>11</sup> Beloved, if GOD so loved us, we also must love one another.

<sup>12</sup> No one has ever seen GOD. Yet, if we love one another, GOD remains in us, and His Love is brought to perfection in us.

<sup>13</sup> This is how we know that we remain in Him and He in us, that He has given us of His SPIRIT.

<sup>14</sup> Moreover, we have seen and testify that The Father sent His Son as Savior of the world.

<sup>15</sup> Whoever acknowledges that JESUS is The Son of GOD, GOD remains in him and he in GOD.

<sup>16</sup> We have come to know and to believe in The Love GOD has for us. <sup>2</sup>

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<sup>2</sup> 2, NAB, I John 4:10-16.

[The wife seems much more at peace now. I thank her - and her husband - for allowing me to be with them. I made the wife aware of Chaplain support available and made arrangements for a follow up Chaplain visit to be offered the next day.]

## **V. PATIENT EVALUATION**

**PHYSICAL CONCERNS:** The patient is totally unresponsive on a ventilator. Wife's concerns are 1. that her husband not suffer; 2. that he not "pine away" in a vegetative state; 3. that as there is zero chance of the patient recovering even partially, that the ventilator and other life support be removed.

**PSYCHOLOGICAL CONCERNS:** The patient and wife have been married for many decades in a loving and happy relationship. The wife and adult children have discussed this very possibility with the patient in the past. His wishes, and the family's, are that he not be kept alive in a vegetative state on life support. The wife already knows what she and their children will do – remove the patient from ventilator – but she is struggling with feelings of misplaced guilt for making this decision, "Is this murdering him to remove the ventilator?" From Church Catechism, I was able to offer sound and certain answers that it was not.

**SOCIOLOGICAL CONCERNS:** The wife is fearful of impending life as a widow and living alone without her beloved husband after being happily married x 50+ years.

## **VI. SPIRITUAL ASSESSMENT USING THE “FICA” MATRIX: FAITH-IMPORTANCE-COMMUNITY-APPLICATION**<sup>3</sup>

1. ***Faith***: Protestant. The patient and wife have attended non-denominational Chapel services and developed a relationship with the staff Pastor at their retirement village for the last two years. Prior to this they regularly attended a Protestant Church for most of their 50 years of married life.

2. ***Importance and Influence***: Prayer and Scripture reading are important to them. Wife has a sense of GOD’s Presence with her. Prayer and Scripture reading are important expressions of her Faith.

3. ***Community***: Wife has been cut off from her Faith community at the retirement village for last several days. She has not called her Pastor to tell him that her husband is dying, that he is “comatose” on a ventilator and that she is struggling with the question of removing life support from him. She has been at her husband’s bedside almost constantly for several days. She verbalizes plans to contact her Pastor.

4. ***Application***: Wife asks for the Chaplain at the bedside of her husband and shares freely. She finds great comfort and reassurance of GOD’s Presence with her after Scripture reading and prayer. Wife is torn between application of Faith in preventing needless suffering and respecting dignity of life versus Commandment against murder. Her misplaced guilt was relieved with clear answers from The Catholic Catechism that withdrawing the extra-ordinary care of life support in this case was well within The Teachings of The Church as a gift of “disinterested charity” of “palliative care” and was in no way “euthanasia.”

## **VII. CHAPLAIN EVALUATION**

I grieved deeply for this poor lady, her husband and their family. My family and I faced the same situation when my father had a massive hemorrhagic stroke in 1991 that left him totally unresponsive and brain dead above the brainstem. He was intubated in the ER and placed on a ventilator.

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<sup>3</sup> 3, Dr. Christina M. Puchalski, MD. “FICA Spiritual History Tool.” 1996. The GW Institute for Spirituality & Health. <https://smhs.gwu.edu/gwish/clinical/fica/spiritual-history-tool>.

But within 48 hours it was clear that there was no chance of him becoming conscious again, much less functioning anywhere near a normal quality of life level. My Dad and Stepmom had long ago discussed this possibility and had decided against futile heroic life sustaining care in such situations.

We withdrew the ventilator on the 3<sup>rd</sup> day. However, my father continued to have vital signs for 2 days further. We made him “comfort care,” i.e. “palliative care.” I was with my stepmother at my father’s bedside when clinical death at last arrived. My stepmother was talking to me and I observed my father stopped breathing. I waited several minutes as my stepmother continued to talk to me, unaware of what I was observing. I went to my father’s other side and took his hand, casually monitoring his pulse in his wrist.

I felt the last few heartbeats of his pulse. I waited several minutes more. When I was sure that my Dad had passed on, I told my Stepmom, “He’s gone.” She fell into my arms crying uncontrollably for what seemed like an eternity.

So I empathized deeply with this family. I understood their pain and sorrow very well. This allowed me to be as sensitive and supportive as I was. I have received enough healing from GOD for my own family’s loss, that I was able to offer myself as a center of The Lord’s peace and reassurance.

## **VIII. PASTORAL CONCERNS**

George Burn, in his article “A Life-context Approach for Developing End-of-life Decisions,” focuses on how to approach patients and their families in preparing for end-of-life care decisions.<sup>4</sup> The best resource is the patient and the family themselves. Such things are best addressed in advanced directives or health care proxies before catastrophic illness or injury come upon people. Unfortunately, it is still the minority of patients and families that make such preparations.

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<sup>4</sup> 4, “A life-context Approach for Developing End-of-life decisions.” George A. Burn, BCC. Chaplaincy Today – The Journal of The Association of Professional Chaplains. Volume 24, Number 1, Spring/Summer, 2008, p 23-25.



Helping patients and families focus on what their convictions and wishes are in the midst of the crisis situations of grave conditions in the hospital is the next best thing. Burn sees 3 areas of discussion that people may be guided through: 1. Creating a context for discussion; 2. psychological and spiritual issues; 3. monetary issues and benevolence.

In my pastoral care, I met this family member within the context of our mutual Christian Faith. I did not impose my solutions on the wife, but helped her see more clearly where she and her family were going with these issues and how GOD was with them. I helped the wife identify her feelings, fears and concerns. I gave her a sympathetic listening ear. I provided concrete and clear answers to her end of life questions. And at the appropriate time, I offered Scripture and prayer for all these things.

## **IX. THEOLOGICAL CONCERNS**

The Psalmist writes in PSALM 56:1-4, “Be merciful unto me, O GOD: for man would swallow me up... What time I am afraid, I will trust in Thee. In GOD I will praise His Word, in GOD I have put my trust; I will not fear what flesh can do unto me.”<sup>5</sup> I worked to help this lady find reassurance in her trust of GOD.

Saint James says in JAMES 5:10-11, “Take, my brethren, the prophets, who have spoken in The Name of The Lord, for an example of suffering affliction, and of patience. Behold, we count them happy which endure. Ye have heard of the patience of Job, and have seen the end of The Lord; that The Lord is very pitiful, and of tender mercy.”<sup>6</sup> My hope for the wife of this patient was that The Lord gave her the strength to endure seeing the suffering of her husband, trusting in The Mercy of GOD, enabling her to ask for help from her Pastor and knowing it was okay to make the decision of withdrawal of life support if they wished.

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<sup>5</sup> 5, KJV, PSALM 56:1-4.

<sup>6</sup> 5, KJV, JAMES 5:10-11.

Saint Paul says in ROMANS 8:18, “For I reckon that the sufferings of this present time are not worthy to be compared with The Glory which shall be revealed in us” in CHRIST.<sup>7</sup> My heart went out to this lady, as she sat there crying at her husband’s bedside. She cried for her husband’s suffering, that of her children and grandchildren, as well as her own heartache. My prayer for this lady and her family was that their suffering would pass quickly, and that GOD would surround them with His Presence, using me as an agent of hope in our future glory and joy with CHRIST in Heaven.

Saint Paul writes in II CORINTHIANS 1:3-6, “Blessed be GOD, even The Father of our Lord JESUS CHRIST, The Father of mercies, and the GOD of all comfort; Who comforteth us in all our tribulation, that we may be able to comfort them which are in any trouble, by the comfort wherewith we ourselves are comforted of GOD. For as the sufferings of CHRIST abound in us, so our consolation also aboundeth by CHRIST.”<sup>8</sup> I prayed for GOD’s mercy and comfort in CHRIST for this lady, that her Faith in The Lord would be used by GOD to reassure her of our sure hope in Him.

Moses writes in EXODUS 20:13, “You shall not murder,” as recorded in The New King James Version.<sup>9</sup> The rendering in The King James Version is inaccurate, “Thou shalt not kill.”<sup>10</sup> The Hebrew Old Testament reads: LO’ TRETSACH<sup>11</sup> - לֹא תִרְצַח - literally, “Not you shall murder.”<sup>12</sup> The family choosing to remove this patient from the ventilator in these circumstances is not murder. It is enabling the dignity of the patient to be preserved and his suffering to not be prolonged in futile, pointless efforts.

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<sup>7</sup> 5, KJV, ROMANS 8:18.

<sup>8</sup> 5, KJV, II CORINTHIANS 1:3-6.

<sup>9</sup> 6, NKJV, EXODUS 20:13.

<sup>10</sup> 5, KJV, EXODUS 20:13.

<sup>11</sup> 7, BHS, EXODUS 20:13.

<sup>12</sup> 8, Strong’s Data, 7523, RATSACH - רָצַח - to murder, to slay, to intentionally kill with premeditated malice.

The Catechism of The Catholic Church teaches a very reasonable balance between respecting and preserving human life and dignity with the removal of extra-ordinary care in futile cases and alleviating human suffering. The choice of this family to remove their loved one from ventilator support in this situation was fully in accord with what The Catholic Church teaches and my Faith as a Catholic Christian. The wife's Protestant Christian convictions agree with both.

The clear prohibition against murder: CCC 2258 "Human life is sacred because from its beginning it involves the creative action of GOD and it remains for ever in a special relationship with The Creator, Who is its sole end. GOD alone is The Lord of life from its beginning until its end: no one can under any circumstance claim for himself the right directly to destroy an innocent human being." <sup>13</sup>

Further: CCC 2261 "Scripture specifies the prohibition contained in The Fifth Commandment: "Do not slay the innocent and the righteous." The deliberate murder of an innocent person is gravely contrary to the dignity of the human being, to The Golden Rule, and to the holiness of The Creator. The Law forbidding it is universally valid: it obliges each and everyone, always and everywhere." <sup>14</sup>

Direct active euthanasia is prohibited: CCC 2277 "Whatever its motives and means, direct euthanasia consists in putting an end to the lives of handicapped, sick, or dying persons. It is morally unacceptable. Thus an act or omission which, of itself or by intention, causes death in order to eliminate suffering constitutes a murder gravely contrary to the dignity of the human person and to the respect due to The living GOD, his Creator. The error of judgment into which one can fall in good faith does not change the nature of this murderous act, which must always be forbidden and excluded." <sup>15</sup>

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<sup>13</sup> 9, CCC, # 2258, p 602, "Article 5, The Fifth Commandment," on the sanctity of human life and The Biblical Commandment of EXODUS 20:13, "Thou shalt not murder."

<sup>14</sup> 9, CCC, # 2261, p 603.

<sup>15</sup> 9. CCC, #2277, p 608, "Euthenasia."

However, futile extra-ordinary medical and nursing intervention, in the face of a hopeless prognosis, is inappropriate. CCC 2278 “Discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to the expected outcome can be legitimate; it is the refusal of "over-zealous" treatment. ***Here one does not will to cause death; one's inability to impede it is merely accepted.*** The decisions should be made by the patient if he is competent and able or, if not, by those legally entitled to act for the patient, whose reasonable will and legitimate interests must always be respected.”<sup>16</sup>

Palliative care to relieve human suffering that does not intentionally cause death, is appropriate in hopeless cases: CCC 2279 “Even if death is thought imminent, the ordinary care owed to a sick person cannot be legitimately interrupted. The use of painkillers to alleviate the sufferings of the dying, even at the risk of shortening their days, can be morally in conformity with human dignity if death is not willed as either an end or a means, but only foreseen and tolerated as inevitable ***Palliative care is a special form of disinterested charity.*** As such it should be encouraged.”<sup>17</sup>

## **X. PLANS FOR NEXT VISIT**

I referred this case to a Chaplain colleague for the next day, important especially in the event the couple’s Pastor is not able to be present. I later learned the patient passed on 2 days later. The wife and adult children made the decision to withdraw ventilator support as planned the day after I visited.

## **XI. LEARNING GOALS**

1. To continue to discern if GOD is calling me to a fulltime hospital Chaplain ministry or elsewhere. The biggest hurdle is can I do this physically, in view of my health. Met. I now have a clear sense that GOD is calling me to hospital ministry in some capacity and that I can do this work.

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<sup>16</sup> 9, CCC, #2278, p 608, “Euthenasia.”

<sup>17</sup> 9, CCC, #2277, p 608-609, “Euthenasia.”

2. To continue to improve my empathetic listening ministry skills, the giving of myself in GOD's Name to the suffering, and how to better give comfort to those in pain. Met. I gently refused to allow myself to answer this lady's question of what exactly she should do. Instead, I helped her own what she and her family had already decided and refute misplaced guilt. To do this, I had to listen empathetically and carefully with compassion.

3. To set and keep limits around my hospital Chaplain work, going home when my shifts end, and to keep time reserved for personal, family and Faith life. Partly met. I was tempted to spend more time with this lady, but had other cases I had to see. I was not available to revisit the next day, and so made arrangements for a Chaplain colleague to do so.

4. To explore and experience further appropriate sharing of empathetic tears with the suffering, while keeping centered on my pastoral care for others. Met. I cried inside for this lady, the patient and their family. I did not overtly cry or become tearful. That would have been contrary to what this lady needed in me at this time, which was a solid rock center of GOD's Peace with certain answers from The Church about end of life issues.

5. To continue to experiment with and expand my use of chants and hymns in hospital Chaplain ministry. Not met. I missed opportunity to quietly chant a Scripture for this lady, as opposed to reading it, which might have offered a further sense of peace in GOD for her.

## **XII. REFERENCES**

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