I. BASIC PATIENT DATA

Chaplain – Robert Baral

Patient – AB, 45+ year old female, marital status not given

days in hospital – 8

length of visit – 40 min

Unit – Surgical Intensive Care Unit

Religion – African Methodist Episcopal Church

Significant Others – Uncle & retired Pastor, sister, son & daughter-in-law, daughter & son-in-law; 2 grandchildren; others – total of 10 loved ones Theme –

"Breaking Through Barriers in a Terminal Withdrawal of Life Support Case: Feelings, Fears and Tears Not Shared in Conversation Released in Prayers."

II. FACTS OF THE CASE

I was on Surgical ICU following up a trauma admit from the Emergency Room a ¹/₂ hour before end of my shift. I was referred to a family in the waiting room by the secretary. They were reportedly "grieving and making care decisions" for patient, meeting with the Doctor now. I reported to the patient's Nurse, who informed me the family might make the patient "comfort care." The Nurse observed the son was especially struggling and asked me to visit with them now.

This is a 45+ year old lady on a ventilator who has no purposeful neurological function, no spontaneous breathing and had now just failed "brain death" testing twice. The patient was admitted about 1 week ago for a mild stroke. She was conscious at that time, complaining only of arm weakness. Mrs. B suffered a cardiac arrest and was resuscitated several days later, then had a 2nd and this time catastrophic stroke. She has now been unresponsive and on life support for 5 days.

III. BACKGROUND INFORMATION

I met with about 10 family members in the Surgical ICU family room. This appears to be a very close family. They are all dressed prim & proper, have a reserved demeanor and politely welcome me into their midst. There was an older family member, the patient's uncle, who is an ordained African Church of GOD Pastor. There were 2 couples, including the son of the patient and his wife; the daughter and her husband; 2 of the patient's grandchildren - a boy of 11 years old and a girl of 7 years. Faith, prayer and being together appear to be central to their understanding and coping with this present crisis.

IV. CHAPLAIN'S PREPARATION

I had a brief time to meet with the Nurse at bedside before joining the family. I prayed silently as I walked, "GOD, help me to help these people!" I was conscious of my own family's experiences involving the painful decisions of withdrawal of life sustaining extra-ordinary care and placing dying loved ones on comfort care. I made a mental check to not impose my own experiences on this family, but to listen empathetically through them, paying close attention to their pain over my own.

V. INITIAL OBSERVATIONS

As I approached the patient's room, the door was closed. I knocked and was invited in by the Nurse. The patient is a middle aged lady, head slightly elevated, on a ventilator. I noted that the patient had no legs due to an old above the knee amputations related to diabetes. No family was at the bedside. After talking to the Nurse, I said a brief prayer for GOD's peace for the patient, family and staff.

As I approached the family room, the door was open. There were 10 loved ones sitting and standing in the room and doorway. They looked sullen and were all silent. They had just met with the Doctor about possible end of life care choices. In the corner of the room was an older, very well dressed man, a family member and retired Pastor. There were 2 middle aged couples, including the son whom the Nurse was especially concerned about.

There was a male teenager sitting with his legs up to his chest on the floor next to the older man. A quiet and obedient little girl was sitting on her mother's lap. The child had an elaborate and beautiful arrangement of hairclips in her hair and a gentle smile. Both children seemed well cared for and secure in the midst of their loving family.

VI. THE VISIT

E = Pastor Z, patient's elderly uncle, a Minister and spokesman for the family regarding Faith issues

S = Son Y

W = the patient's sister W, knowledgeable of events and spokesman for family regarding the medical situation

F = other family members

C = Chaplain

C1 – [I approach family in doorway of family room] Hello. Are you the B family?

F1 – Yes.

C2 - I am Bob, one of the hospital Chaplains. [Immediate eye contact. I extend my hand to the nearest family member.]

S1 – [Son offers me a firm grip and we shake hands] Thank you for coming to see us, Chaplain Bob. I'm Y, A's son.

C3 – It is my privilege. I was talking briefly with A's Nurse, and she asked me to see if I could offer to spend a few minutes with you. Would that be okay?

F2 – Yes, come in.

C4 – Thank you. [There are 10 family members crammed into this little room and in the doorway. There is 1 empty seat in the corner. I go from oldest to youngest, make eye contact with each and offering my hand to each as they tell me their names.]

C5 – May I have a seat here with you?

F3 – Yes. Please sit down.

C6 – [I sit down. I am facing the entire family now.] I understand from the Nurse that you have met with the Doctor and are struggling with care decisions.

F4 – Yes. [Brief awkward silence. I am conscious that they are studying me. I hear their silent questions, "Can we trust this man enough to share our pain with him? Is he one of us or an agent of the hospital? Is he a faithful Christian man or a liberal heretic?"]

E1 – Are you part of a denomination? What Faith are you? Do you believe in JESUS CHRIST and The Holy Bible? Are you baptized in The HOLY SPIRIT?

C7 – [Gauntlet question. I must pass their test or this visit is finished.] I am a devout Christian. JESUS CHRIST is my Lord and Redeemer. I treasure and study His Word every day to guide me. The SPIRIT of The LORD is my strength. I've just graduated from a conservative Episcopal seminary a few months ago.

E2 – How long have you been a Chaplain here?

C8 – [Another gauntlet question. They are wondering if I have any experience and if I'm qualified to minister to them. I must be careful not to either oversell or undersell myself. I am conscious of the commanding presence of this venerable older gentleman.] I've been with the hospital as a Chaplain for one year, part time. I've just begun fulltime last week.

E3 – I see. Well, I'm Pastor Z, semi-retired now, A's uncle. [He smiles and nods his approval of me to his family.]

C9 – [Time to shift the conversation back to the family.] Thank you for letting me share that, Pastor Z. May I ask what brought A into the hospital? W1 – She had a stroke. [I shift my attention and eye contact to this middle age lady, who speaks up directly.] I'm W, A's sister.

C10 – And when was that? [I lean forward and remain silent]

W2 – She came in last week with arm discomfort. They said she had a small stroke.

C11 – [The lady is answering in short bullet replies.] W, was she awake when she came in?

W3 – Yes. She was doing well. But then she coded over the weekend and had a second very large stroke. They had to intubate her and put her on a ventilator. [This lady seems to be ready to open up a bit.]

C12 – [I reflect back. This lady is using language that suggests she is knowledgeable about healthcare. She seems to be the key family member that processes the patient's medical situation for the family.] So A came in last week with arm discomfort and she had a small stroke. But then her heart stopped for a time and she had a second and much bigger stroke. They had to intubate her. And has she been on a ventilator since then?

W4 – Yes. [The lady relaxes her shoulders. She shares several sentences in rapid succession. She has had to tell this to a lot of people.] A is not breathing on her own. There's no chance of her recovering or waking up. C13 – [I nod my head slowly.] I see. [short pause] I understand that you all were talking with A's Doctor and that you are struggling with what to do next?

E4 – We just have to wait on GOD.

C14 – [I turn to face Pastor Z again.] Pastor Z, I see you all find your strength in difficult times like these in faith in our Lord.

E5 – Yes. We are all in His hands. Most of us are African Methodist Episcopal. But I'm a Pastor with The Pentecostal Church of CHRIST in the city not far from here. Do you know what Church that is?

C15 – Yes, Pastor. I've met others from your Church here as a Chaplain. E6 - I've been a Pastor for 50 years.

C15 – That's a long time serving The Lord. You've been a Pastor for about as long as I've been alive! [brief pause] May I ask how you see GOD working in this situation now?

E7 – They've done everything they can. We have to wait and see what GOD's will is, if He will call her Home, or if He will keep her here longer.

C16 – [Only the Pastor and sister have shared with me. The other family are understandably withdrawn and despondent. I think, maybe I should look to give them back their privacy, so they can prepare to grieve together.] I am wondering if you would like me to pray with you all and then give you back your privacy?

- E8 That would be wonderful, Chaplain Bob!
- C17 Pastor Z, would you like to lead in prayer?
- E9 No, Chaplain Bob. Would you please lead us?
- C18 I would be happy to. May I offer a Scripture, if you would like?
- E10 That would be good.
- C19 Do you want me to read any particular Scripture?
- E11 No. You choose.
- C20 I read from the following:

PSALM 56:1-4:

- 1 Be merciful to me, O GOD...
- 3 Whenever I am afraid, I will trust in You.
- 4 In GOD (I will praise His Word),
- in GOD I have put my trust;
- I will not fear. What can flesh do to me?¹

PSALM 57:1-2:

Be merciful to me, O GOD, be merciful to me!
 For my soul trusts in You;
 and in the shadow of Your wings I will make my refuge,
 until these calamities have passed by.
 I will cry out to GOD Most High,
 to GOD Who performs all things for me. ²

C21 – [All the family become quietly tearful. I am conscious that I feel tearful with them. I look around briefly to all of the family.] Let us pray. [I stand up and offer my hands, to my left is Pastor Z and to my right is Mrs. B's son Y. They in turn all stand and close the circle. The children are tenderly included with holding of hands.]

¹ 1, NKJV, PSALM 56:1-4.

² 1, NKJV, PSALM 57:1-2.

C22 – [I pray for GOD's peace and comfort for the patient, acknowledging her soul is safe in The Arms of JESUS. I pray for GOD's hand of encouragement and strength for the family, acknowledging that The HOLY SPIRIT is in their midst. I pray that GOD The Father would keep us all under the shadow of His wings forever, and that His Mercy would flow down upon A's family from this generation to thousands of generations now and forever. And then I stop and remain silent. I keep hold of their hands.] F4 – [The family members begin to pray in subdued audible tones, growing louder and passionate. As one prays, the others pray in the background, until all the adults have done like wise.] Thank You, JESUS CHRIST! Thank You, Lord GOD!

C23 – [When the family's vocal prayers subside, I conclude] And now, Lord JESUS, we pray together to You in The Words that You teach us, saying "Our Father, Who art in Heaven..."

F5 – [The family joins me in voicing The Our Father.]

C24 – [I let go of their hands. I open my eyes. Our prayer has taken about 20 minutes of the visit. A tissue box is passed.] Thank you for letting me be with you tonight. I want you to know you can have the Chaplain called if you need us at any time, please just have the Nurse page us. I will keep you all in our prayers!

C25 – [Starting with Pastor Z, I go to each one and take their hand.] Thank you.

C26 - [I bend forward at eye level with the children, each sitting enwrapped in their mothers' arms. These beautiful children look into my eyes and smile at me with such warmth and gentleness. They take my hands and squeezes for a moment.] I know that your GrandMom A will be loving and praying for you forever, where ever you go in your lives. She will always be smiling on you with The Love of JESUS. [The children say thank you and continue to smile gently at me. I will especially remember these children's eyes and smiles for a long time, maybe forever. I exit.]

C27 – [The patient was withdrawn from life support the next day and passed on, their family having the support of their Church and another Chaplain.]

VII. SPIRITUAL ASSESSMENT RESUME HERE

 Spiritual distress to despair related to impending decision of withdrawing ventilator support for patient; 2. Emotional numbness related to accepting reality that patient is brain dead and will not recover;
 Concern that patient not experience any further avoidable pain and suffering; 4. Anticipatory grieving realizing that patient almost certainly will die quickly if and when ventilator is removed;

5. Seeking comfort and strength with faith in GOD and fellowship with one another; 6. They are under severe stress in this crisis, but their Faith is meeting their needs for strength and coping – at least externally and in the immediate present; 7. They are facing the question, "Is it GOD's will for us to remove our loved one from the ventilator, or to keep the extra-ordinary care going, and how to wait for GOD to act further in each scenario?"

VIII. PASTORAL SPIRITUAL CARE PROVIDED

1. Identified myself and asked for permission to visit; 2. Addressed their questions and gave my attention and eye contact, from the eldest to the youngest, not neglecting anyone; 3. showing respect to the eldest loved one first, the uncle and spiritual head of the family, who is an ordained Minister; 4. attentive listening; 5. reflecting back to see if I understood the situation and so they knew they were heard; 6. in view of despondency, kept questions brief and minimal; 7. offered and provided prayer and Scripture reading;

8. Left space open for each loved one to verbalize a spoken and unspoken prayer, each in turn, as they wished; 9. offered therapeutic touch of holding hands during prayer; 11. thanked each loved one for allowing me to visit and pray with them; 12. made special point of giving simple pastoral reassurance to the children present, that their GrandMom will always be loving and praying for them; 13. made family aware of further Chaplain support and arranged for same; 14. reported back to Nurse and left Pastoral Care Dep't card at bedside.

IX. OBSERVED OUTCOME

Family shared guardedly, many were reserved and in deep despair. Two key figures in family shared somewhat freely, the patient's sister, who explained the medical situation to me, and the patient's uncle Pastor, who shared how they saw GOD working as source of strength and comfort for them. Before they risked sharing with me as merely "a hospital Chaplain," they required me to pass several gauntlet questions to see if they could take that risk. Answering directly and honestly, I became "their hospital Chaplain" and was able to focus on their story thereafter.

The family was very devout in their Christian Faith. At the end of visit, all of family stood with me, held hands and took part in prayer, which seemed to be a very helpful release for them, taking up the entire 2nd half of our visit together. I shared the same concern held by the patient's Nurse for the son, observing in particular he was not able to share much.

The authority and presence of the patient's uncle Pastor and sister who addressed their spheres of expertise both relieved the son from having to do so, and may have also stifled his needing to do so. The lengthy prayer and release of tearfulness indicated a reduction of some spiritual distress in the circle of a close loving family with a deep and helpful Faith.

X. ALYSIS OF PATIENT/FAMILY

1. What is GOD's will for us in this situation? Is it that we should allow our loved one to continue to be supported artificially on a ventilator and related care when we've learned there is no hope of recovery? Or is it that we should remove life support? 2. Which ever we choose, GOD will work His will for our loved one and us in this circumstance. 3. The answer to what we should do is not immediately clear. But we do not need to make this decision now. GOD will show us what the right decision is. 4. In either case, GOD will call our loved one Home to Heaven in His time.

XI. PSYCHOLOGICAL, SOCIAL AND CULTURAL ISSUES

1. The family was initially suppressing their heartache within their Faith, social and family expectations of maintaining demeanor and hierarchy. 2. They did however, allow themselves to show tears and pray fervently with me in their Tradition – a combination of High Church and Black Pentecostal – for the 2nd half of our visit for about 20 minutes.

3. The extended prayer served as a release of fears and anxieties that was culturally, socially and psychologically acceptable in their world, while still allowing them to maintain their life expectations of respect for hierarchy and a keeping a reserved peaceful Christian demeanor. Therefore, once I had gained their trust and came to be seen as CHRIST-like to them, an acceptable intimate stranger as their Chaplain, the visit succeeded in helping them very deeply.

4. They are clearly a close, loving and mutually supportive family.5. I wondered, if the strong patriarchal uncle Pastor and the in charge matriarchal sister were absent, if other family members would have been able to help family cope as well, and if any of them would have been able to express their feelings at all.6. I was careful not to push any limits or force them to explore where they were not ready to go.

7. I observed that what they were not ready to share now in pastoral conversation, they were very able to share in prayers with me. 8. I have noted the traditional and hierarchical structure of this family, which I showed respect for. 9. The family's Faith Tradition seems to place high value on order, self control and dignity.

10. As a white man, I was likely seen at first as an out intruder to this close black family. It was necessary for me to pass their evaluations before they consented to share a little and to allow me to pray with them. I was not conscious in myself of a racial barrier here, but I am aware that many non-whites I minister to carry this baggage in our society today. I find such barriers usually very easy to overcome by showing empathy and respect, entering humbly with a gentle spirit, asking permission and looking for traditions I share across such lines that I can use as bridges.

XII. MINISTRY ANALYSIS USING THE 8 BEATITUDES

Saint Matthew records that our Lord JESUS CHRIST, upon "…seeing the multitudes, He went up into a mountain: and when He was set, His disciples came unto Him: And He opened His mouth, and taught them, saying:" ³

³ 2, KJV, MATTHEW 5:1-2.

MATTHEW 5:3, "Blessed are the poor in spirit: for theirs is The Kingdom of Heaven." ⁴ Lord, You help us to keep our focus on The Cross and not on ourselves when ever and how ever we are called to minister to hurting people in Your Name.

MATTHEW 5:4, "Blessed are they that mourn: for they shall be comforted." ⁵ Lord, You hear our cries and records all our tears. You call all who minister to not suppress the tears of the suffering, but to give them permission to offer them up to You, to others and to themselves.

MATTHEW 5:5, "Blessed are the meek: for they shall inherit the earth." ⁶ Lord, only You can give us daily the hearts of faithful servants of The Cross. Keep us from self pride, knowing that You are present in and with all these people that You send us to comfort.

MATTHEW 5:6, "Blessed are they which do hunger and thirst after righteousness: for they shall be filled." ⁷ Lord, You call us to hunger and thirst after Your righteousness, and not that of the world. Use us as Your instruments to guide the suffering to Your righteousness, that their hearts may be satisfied in You.

MATTHEW 5:7, "Blessed are the merciful: for they shall obtain mercy." ⁸ Lord, that you call us to have mercy and pity on the afflicted, as You have mercy and pity for each of us.

MATTHEW 5:8, "Blessed are the pure in heart: for they shall see GOD." ⁹ Lord, You help us keep our hearts fixed upon You, that we may behold Your Beauty in part now and then forever. Fill us with the joy of this great consolation, and work through us to call the grieving towards That same Beauty.

⁴ 2, KJV, MATTHEW 5:3.

⁵ 2, KJV, MATTHEW 5:4.

⁶ 2, KJV, MATTHEW 5:5.

⁷ 2, KJV, MATTHEW 5:6.

⁸ 2, KJV, MATTHEW 5:7.

⁹ 2, KJV, MATTHEW 5:8.

MATTHEW 5:9, "Blessed are the peacemakers: for they shall be called the children of GOD." ¹⁰ Lord, You call us to be instruments of Your peace for those in distress. May we learn to offer up our own burdens as spiritual offerings for others, that we may be peacemakers as Your children.

MATTHEW 5:10-12, "Blessed are they which are persecuted for righteousness' sake: for theirs is The Kingdom of Heaven. Blessed are ye, when men shall revile you, and persecute you, and shall say all manner of evil against you falsely, for My Sake. Rejoice, and be exceeding glad: for great is your reward in Heaven: for so persecuted they the prophets which were before you."¹¹

Lord, You alone give victory to us Your people over - not just darkness and sin - but over death itself. You alone bestow upon us new life in this world and eternal life in Heaven with You. Loosing a loved one to death is the ultimate human persecution, but You have already won for us The Victory by Your Passion, Death, Resurrection and Ascension. AMEN!

XIII. ANALYSIS USING CATECHISM OF THE CATHOLIC CHURCH

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 – as long as death is not the primary objective to be caused. The prognosis of this patient's recovery being zero, inflicting needless and futile extra-ordinary care was unwarranted.

While I fully agreed with the eventual decision of removing the patient from life support in this case, I offered no advice, nor was I asked to render an opinion. My method is to reflect back the facts and feelings that people share with me in such cases, identify information and pastoral resources, answer specific questions if asked within the scope of my Ministry practice and accompany people as they make their own decisions.

¹⁰ 2, KJV, MATTHEW 5:9.

¹¹ 2, KJV, MATTHEW 5:10-12.

We must start with the fact that all human life is precious. 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." ¹²

Murder is a grave sin: CCC 2261, "Scripture specifies the prohibition contained in The Fifth Commandment: ¹³ "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:" ¹⁴ EXODUS 20:13, "You shall not murder." ¹⁵

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." ¹⁶

However, futile extra-ordinary medical and nursing intervention, in the face of a hopeless prognosis, can become 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...

¹² 3, 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."

¹³ 1, NKJV, EXODUS 20:13, "You shall not murder," correctly translated from Hebrew.

¹⁴ 3, CCC, # 2261, p 603.

¹⁵ 1, NKJV, EXODUS 20:13.

¹⁶ 3, CCC, #2277, p 608, "Euthanasia."

... 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." ¹⁷

Therefore, palliative care to relieve human suffering that does not intentionally seek to cause death is appropriate in hopeless cases. This can include the decision to remove a patient from life support in such 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."18

XIV. FUTURE PASTORAL OPPORTUNITIES PRESENTED

1. Continue to enter in gently and listen a lot. 2. Continue to show respect to people in all cases. 3. Continue to invite people as active in, or passive with, prayer when provided. 4. Continue to be sensitive to racial, ethnic and denominational barriers. 5. Increase creative opportunities for people to express their feelings if and when they are ready, realizing at times people may not be able to talk about their feelings, but may be able and ready to share them through prayer - verbal and non-verbal - religious Icons and Sacramentals, Holy Scripture, formal prayers and liturgy, informal felt prayers, religious readings, poetry, tears, smiles, holding of hands, art, embraces, holding of hands, holy silence, pastoral presence.

XV. CHAPLAIN SELF REFLECTION

1. I empathized deeply with this family. I pictured my sister-in-law and my father who, both of whom were on ventilators before their deaths. I recalled how my StepMom and I struggled with the decision to withdraw ventilator support from my Dad when he was brain dead and there was no hope for his recovery. As opposed to my young sister-in-law, for whom intervention was maximally aggressive to the last moment.

¹⁷ 3, CCC, #2278, p 608, "Euthenasia."
¹⁸ 3, CCC, #2277, p 608-609, "Euthanasia."

2. As a Nurse, pictures of the many ventilator cases I cared for circulated vaguely in the back of my mind. They make me shudder at times, requiring internal awareness to avoid entering into a "fight or flight" emotional state, which would incapacitate my ministry care. Under control, these professional and personal experiences help me to reach out with greater empathy.

3. The question of the suffering and often pointless care inflicted upon people by the modern medical system is of great concern to me, often providing false hope, the desecration of human dignity and man attempting to play GOD by denying man's mortality.

4. I was relieved for this family to learn that their ordeal ended by the next day after removal of life support for the patient. Although sad at the loss, I have the certainty of Faith, congruent with this family, that their loved one has now met in fellowship with my own departed loved ones at The Lord's Table in Heaven.

5. The Catechism of The Catholic Church offers a very reasonable balance between the respect for human life and the reduction of human suffering – Thou shalt not murder vs. not inflicting pointless aggressive interventions in a clearly hopeless case. Used carefully and within the scope of one's Ministry, this information can be very helpful to people dealing with such terrible struggles. I was not asked for this information by this family. However, I have referred to The Catechism in other such cases, speaking when asked in accordance with The Teachings of The Catholic Church.

XVI. REFERENCES

1. "New King James Version" Bible. <u>http://www.biblegateway.com/</u>.

2. "King James Version" Bible. <u>http://www.biblegateway.com/</u>.

3. "Catechism of The Catholic Church." U.S. Conference of Catholic Bishops. <u>http://ccc.usccb.org/flipbooks/catechism/index.html</u>.