

Data

Chaplain: Robert Baral

Pt: XY, late 50s year old male

Time of Visit: 11:30

Length of Visit: 30 minutes

Type of Visit: follow up

Location of Ministry: Intensive Care Unit

Title:

“Alone in the Darkness Facing Death: Accompanying Those in Despair”

Diagnosis & Prognosis:

Respiratory Failure and terminal bone marrow disease. Poor prognosis.

Peer group focus:

What is the best way to offer the gift of self to those who feel deeply alone?

Introduction:

Mr. X Y is a late 50s year old man taken off a ventilator last week for respiratory failure. He remains in ICU. He is visibly short of breath at rest. He has a chest tube on each side. His Nurse reports he was told last week that he has a terminal bone marrow disease, and that he is not a suitable candidate for the only thing that might prolong his life, a bone marrow transplant. On previous visits he shared that he has a supportive family locally, but is divorced and was living alone. He has a high school education and was a manual laborer all his working life. He describes himself as “Christian.” He has a right Above the Knee Amputation due to “poor circulation” 3 years ago. This is my 3rd visit with him.

The Text:

P – Patient. C – Chaplain.

C1 – [I enter patient’s room. I knock.] Hello, Mr. Y. It’s Chaplain Bob.

May I come in?

P1 – [Pt opens his eyes.] Okay.

C2 – I’d like to sit with you for a while, if that’s okay. [I offer pt my hand. We shake hands. His grip is weak.] Let me pull up a chair. [I sit.] Now if you’re feeling short of breath from talking, or you need to end our visit, you just say so. Okay?

P2 – Okay.

C3 - I understand that Chaplain A was in to see you last night, and that she prayed with you briefly.

P3 – It's not helping. [Pt closes eyes again.]

C4 – What you have been praying about?

P4 – To get better.

C5 – Your prayer is to get better. How would that look for you?

P5 – Damn Doctors. There's nothing wrong with me! They aren't letting me out of here fast enough!

C6 – [I think, okay, sir. You've just come off a ventilator. You have 2 tubes sticking out of your chest and you're on oxygen. You've been told you have a terminal bone marrow disease they can't cure. Your one leg is missing. And there's "nothing wrong" with you...] It sounds like you feel angry.

P6 – Why don't they let me go home?

C7 – You don't want to be here in the Intensive Care Unit anymore. Who's waiting for you at home?

P7 – My family.

C8 – I know that you've been through a lot. [I sit silently.]

P8 – Too much. [Pt's voice trails off. He turns his head away to hide his face from me. He closes his eyelids tight.]

C9 - [I think to myself, Yes, X, you've been through too much. I feel like I'd like to cry for this man. That tells me he may be on the verge of doing so. I sit quietly with him for several minutes.] I hear that you're in a tough place.

P9 – [Eyes still closed.] Why the hell don't they move me to a regular room? I just want to go home.

C10 – I hear that you'd rather be out of here. And you'd rather just go home to your family at this point. I am wondering, have you been able to talk to your Doctor or Nurse about wanting to do this?

P10 – No. It doesn't matter.

C11 – [I think, GOD, he's getting the \$million dollar workout, but he doesn't want to go on with all this.] I think it matters a lot what you want. Why do you say that, Y?

P11 - I don't know.

C12 – [I'm suddenly suppressing an angry Clash song in my head. Something about being "lost in a rock 'n' roll world." I refocus.] I'd encourage you to tell your Doctors and Nurses outright what you'd like to see happen at this point.

P12 – [Pt opens his eyes again and looks ahead.] They don't give a damn.

C13 – Well, they need to know what your wishes are.

P13 – Well, maybe.

C14 – [I think, he’s on the edge of either telling me to get the hell out or spilling his heart to me. I decide to invite him to give me direction.] X, I hear you are having a difficult time getting through all this. And you aren’t happy with the way things are going. And you feel like you just want to get out of here to a regular bed, or better yet, home to your family. But you haven’t been able to tell your Doctors and Nurses what you want to see happen now. Is that right?

P14 – Yeah, that’s right.

C15 – I’m also wondering if you’d like me to leave or stay with you now?

P15 – It doesn’t matter. Do what you want.

C16 – X, it does matter. If that’s the case, I’ll stay, since you give me the choice. [I offer him my hand. He grasps my hand and I sit in silence with him. He closes his eyelids tight again. I think, GOD, he’s a simple man of few words. He’s had some really hard knocks. He needs to know it’s okay to advocate for his treatment choices.]

C16 – X, would you like me to pray with you about these things?

P17 – No. Not now. But you can keep me in your prayers.

C17 - I would be happy to. I will keep you – and your family – in my prayers today. Would you like me to ask the Nurse to sit with you for a while to talk about what care choices you’d like?

P18 – Okay.

C18 – Your Nurse can help you talk with your Doctor about these choices. I’m going to leave my card here for you. Thank you for letting me see you again. You have the Nurse call for us any time. You rest easy, X. [He makes eye contact with me and expresses thanks. I let go of his hand after a long time and quietly exit the room. I report to the Nurse, who comes to talk with Mr. Y as he wished. A few days later, I find Mr. Y is out of ICU and finally got his “regular room,” is on Comfort Care and is preparing to go home soon on Hospice to his family. I offer up prayers for Mr. Y. and his loved ones.]

Self-Awareness:

1. I wanted to be able to engage the patient, but he was in deep despair and was not able to share much in words. This patient was also short of breath. I spent most of my visit simply sitting at his bedside. I think this is what he needed most, to not be alone in his distress.

2. In spite of his seeming denial and/or ignorance about his grave prognosis - “There’s nothing wrong with me!” - I believe he knew his condition was terminal on some level. But I didn’t come out and say, “So I hear you’re going to die soon. Gee, what a bummer!” Instead, I made sure he knew that I heard what he was sharing in reflecting back to him. And I let him be where he was: his agenda; his pace; his life.

3. He wasn’t able to say, “Please stay with me!” in words. But I got the clear message that he wanted me there. So I stayed until he seemed okay with ending the visit.

4. Mr. Y. was having trouble telling his Doctors and Nurses what he wanted in his treatment: to get out of ICU, go to a “regular room” and simply go home to his family. I wondered if he felt he didn’t have the right to tell them what he wanted. I encouraged him to let his wishes be known. When he gave me permission, I facilitated that conversation between Mr. Y. and his Nurse.

5. David writes in PSALM 34:19, “The LORD is close to the brokenhearted, saves those whose spirit is crushed.”¹ Part of my self awareness as this man’s Chaplain for a time was knowing that GOD was present and listening to this man’s cries. The LORD’s closeness was not dependent on my arrival on the scene. I was also conscious that GOD was using me for a time as an instrument of His Peace, to break this man’s aloneness for a time, and to remind him that GOD was listening.

¹ 1, NAB, PSALM 34:19.

6. I was self aware of consciously letting go of the need to insert my Ego. I held back from sharing my own experience. I surrendered any claim of Mr. Y's time and space together as mine, making them unquestionably his. I gave "the gift of self." As James Miller puts it, I listened in a "Healing way," affirming the belief that suffering is a little more tolerable when people realize they are not alone in their pain, and "...become more complete as... [they] express and claim what they have within them to say."

² This helped me to be more comfortable in the silence with Mr. Y.

Theological Reflection:

I neither prayed with nor read Scripture for this man on this visit. But my heart was thinking King David's PSALM 23:1-6 as I sat with him in the moments of silence:

¹ The LORD is my Shepherd; therefore can I lack nothing.

² He shall feed me in a green pasture, and lead me forth beside the waters of comfort.

³ He shall convert my soul, and bring me forth in the paths of righteousness for His Name's sake.

⁴ Yea, though I walk through the valley of the shadow of death, I will fear no evil; for Thou art with me; Thy rod and Thy staff they comfort me.

⁵ Thou shalt prepare a table before me in the presence of them that trouble me; Thou hast anointed my head with oil, ...my cup shall be full.

⁶ Surely thy loving-kindness and mercy shall follow me all the days of my life; and I will dwell in The House of The LORD for ever. AMEN! ³

Kenneth Haugk, in "Don't Sing to a Heavy Heart," writes, "Just as the shepherd is with his sheep, GOD is with His people. His Presence comforts. It means that, wherever we are, in whatever situation, we are not alone. Not alone! What is more discouraging... than feeling utterly alone? JESUS knew something about loneliness... those who suffer aloneness experience depths of despair poignantly expressed in JESUS' heartbreaking cry on The Cross..., "My GOD, my GOD, why hast Thou forsaken me?..."^{4 5}

² 2, Miller, "The Art of Listening in a Healing Way," p 13. Therapeutic Listening versus Healing Listening.

³ 3, Anglican Revised Book of Common Prayer, PSALM 23:1-6, p 95.

⁴ 4, KJV, PSALM 22:1; MATTHEW 27:46; MARK 15:34.

⁵ 5, Kaugk, "Don't sing Songs to a Heavy Heart," p 27-28. Stephen Ministries.

Aloneness is never so sharp as when someone is suffering. While GOD's Presence can be a powerful antidote to loneliness, suffering people may have a difficult time believing GOD is with them. One gift... [we] can offer them is to be present in their pain. The physical presence of another human being can bring significant comfort to those who are suffering, even with little or no words spoken.

Even more helpful is to have someone with them in mind and spirit – understanding and empathizing with them in their pain. Even terrible pain and suffering can become bearable when people know someone is truly and fully with them. As a caring Christian, you follow The Good Shepherd's example when you walk with them in their dark valleys.”⁶

There was a time in my life when I walked through the dark valley of the shadow of death. I recall then how alone I felt in the midst of my suffering and pain. As a Christian man, I knew in my head that GOD was Present with me. But I could not feel His Presence at that time in my heart. That time was when I was recovering from major surgery for cancer several years ago. I was abandoned by those people in my life that I loved the most. In my suffering, I felt utterly alone, even like JESUS on The Cross.

It was not until my Pastor came to my bedside, sitting with me in my pain, that I knew that I was not alone. I knew he came in The Name of The LORD. And in my Pastor's compassionate presence with me, I knew again that GOD was there with me. I was not alone! And this knowledge gave me the strength to recover. This was the heart of the pastoral care I brought to this patient.

⁶ 5, Kaugk, “Don't sing Songs to a Heavy Heart,” p 27-28. Stephen Ministries.

Lessons in Ministry

Dr. Elisabeth Kubler-Ross offers a five-stage model of *Grief* that she observed many people progress through in processing their own approaching death. The model is not a mechanical universal rigid model, but a framework that can help understand common feelings that many people may experience at different times in the midst of loss:

1. ***Denial and Isolation*** – “At first, we tend to deny the loss has taken place, and may withdraw from our usual social contacts. This stage may last a few moments, or longer.”

2. ***Anger*** – “The grieving person may then be furious at the person who inflicted the hurt (even if he or she is dead), or at the world, for letting it happen. He may be angry with himself for letting the event take place, even if, realistically, nothing could have stopped it.”

3. ***Bargaining*** – “Now the grieving person may make bargains with GOD, asking, ‘If I do this, will you take away the loss?’”

4. ***Depression*** – “The person feels numb, although anger and sadness may remain underneath.”

5. ***Acceptance*** – “This is when the anger, sadness and mourning have tapered off. The person simply accepts the reality of the loss.”⁷

My first purpose was to affirm Mr. Y’s words and feelings. It was not my place to push him through his anticipatory grief, but to sit there with him in it. This patient was experiencing denial, anger, bargaining and despondency. He was not able to openly accept that his condition was terminal. It was for him to work out his own anticipatory grief and not for me to direct or mold it.

Mr. Y had not been able to tell his Doctors and Nurses what he wanted for his care. With his permission, I enabled him to make his care wishes known. I affirmed his unalienable right to make his care wishes known to his caregivers and then facilitated a conversation between the pt and his Nurse about his treatment choices. And I kept him in prayer according to his wishes. It was my privilege to be used by GOD for a short time to help this patient begin to work through his despair and make his care wishes known as he approached his own end of life.

⁷ 6, Kubler-Ross, “Five Stages of Grief.”

References

1. "New American Bible." Bible Works 7. Bible Works, LLC. Norfolk, Virginia. 2006.
2. "The Art of Listening in a Healing Way." James E. Miller. Willowgreen Publishing. Fort Wayne, Indiana. 2003.
3. "The Revised Offices of The Book of Common Prayer, together with Appendices." The 48th General Council of The Reformed Episcopal Church. 2nd Edition. 1997.
4. "King James Version" Bible. Bible Works 7. Bible Works, LLC. Norfolk, Virginia. 2006.
5. "Don't Sing Songs to a Heavy Heart – How to Relate to Those Who are Suffering." Kenneth C. Haugk, Ph.D. Stephen Ministries. Saint Louis, Missouri. 2004.
6. "Five Stages of Grief - Elisabeth Kubler-Ross. "Based on the Grief Cycle model first published in *On Death & Dying*, Elisabeth Kübler-Ross, 1969." Interpretation by Alan Chapman. The EKR Foundation. 2006-2008. Retrieved 1/01/2009.
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