

Jeanne's last 99 days: Husband's perspective (who lost the fight with God)

This illness is not meant to end in death; it is going to bring glory to God – for it will show the glory of the Son of God.

John xi: 4
J. B. Phillips

Abstract

The focus of these notes is to try and get a handle on why Jeanne died in the manner she did and to determine if there are any lessons, for me (or anyone); for sure, I am not looking for cause, blame, or being vindictive and judgmental, although, for sure, some of this will bleed through – I just have to put this on paper so I can get past the absolute devastating disappointment (and horror) of how this sickness did not get fixed, that she did not recover, and that she went through so much misery, pain, and suffering we (inconceivably) could not - it seems - control, manage, change, or modify the planned outcome that was already in place when she got real sick.

These notes are mine and mine alone *ex animo* (from the heart) shared (reluctantly) with just a few very close people noting the details are for mostly me as I am working on getting out of this mist, misery, mystery, and pressing on with a different life I did not ask for - nor appreciate - as this was not my Plan A. These notes reflect the journey from my side, with my daughters hand in hand, and to come to grips with why so much was lost why so much pain and why the tears and prayers did not seem to affect the outcome – the Latin sentiment is *hinc illae lacrimae* “hence these tears.”

Some questions *imprimus* “in the first place” are:

Why?

Why did it take over 14 months to diagnose her illness?

Why did it take 99 days to end her life when God knew when we left Denton for Big Baylor she was not going to make it?

Why did the medical community not be as forth coming about her physical issues (seizers)?

Why did I not pay enough attention to the details of the issues as doctor after doctor filed in and gave their prognostications?

The real questions are *why she did not make it after absolutely doing so well with the five and half hour thromboendarterectomy AND being told on January 1st by the neurologist “there is nothing in this cat scan of her brain to show any reason why she cannot recover.”* We saw green lights! We saw a rock star meeting all the tests she was given! We saw for the first 94 days her body and vitals recover back to normal...then we saw the other shoe fall. God said no.

Looking back at the 99 days I feel she was crucified. I take umbrage to the treatment and conclusion as Jeanne did not deserve or need this from a loving and benevolent God. I really do take umbrage at being pulled through a key hole for 94 days and then pushed back through the same hole in the next five days to pull the plug on Jeanne.

When I disconnected the vent from her trach it caused a sickening feeling in my throat (present now, and with the same *&%# tears) and while watching her die to the very last heartbeat, breath, and gasp - and in my arms – it was a stirring, signal, and striking event I could never dismiss from my mind and heart...Jesus God, why couldn't I have taken her place?

Disclaimers/Cautions/Comments/Claims/ *horrible dictu* “horrible to relate”

(a) Jeanne would probably not be very happy with my Monday morning quarterbacking and in a way I agree but this catharsis is therapeutic for me - and necessary.

(b) I didn't ask to be in this situation – do NOT want to be here and would give my left arm, my left you know what, and all my kingdom to have her back...but we know the answer to that.

(c) Of course I make no claim to know about God, know of God, and especially know of God's plan and will be the first to admit no claim to understand His purpose for Jeanne's dying the way she did. I simply just do not understand, and really think no one else can come any closer; hence, the reason for this systemic diatribe (bitter harangue) to probe for closure I know will not happen any time soon.

(d) Am not looking for any sympathy...or guidance, or direction, or anything as this is a sorting out time for me to get through this anger and press on with my life without my bride; for sure, right now I probably would not be very amenable to suggestions, well meant words, or constructive criticism so thanks anyway. Please, I hope you understand this brash and rather personal remark.

(e) [Very Special Paragraph for me] Something happened to me right after Jeanne went in for her open lung biopsy. I felt like I loved her but my attention became focused on really helping her through the illness and I fell in love with her like I have never loved her before. She became my total focus. I had to get her well. Nothing else but Jeanne mattered. This was a special time for us both – well, the first part – and her last words to me on December 4th were “We will hold hands and grow old together.” My greatest disappointment is not getting the privilege. Our plan A did not work out. Kelly, Lisa, and I had great plans of walking her down the ICU on the second and third floors of Big Baylor and greeting the nurses and doctors who helped her and especially seeing Dr. Shafii so we could have a picture of them together. This was a supreme disappointment for me – and at the end of this note you will see it was a disappointment to someone else.

History of the Sickness

Finis origne pendet “The end depends on the beginning”

On/about January 1, 2013 we started talking to the doctors with Jeanne's symptoms of “I have a cough. It hurts right here in my throat” and after more than one CT, EEG, and blood test a number of doctors looked her over and listened to her heart and lungs...and she passed all tests. The diagnosis went from allergies, asthma, pneumonia, walking pneumonia, bronchitis, to mold in her lungs. Through the summer she had two bronchoscopes, a trip to the emergency room, and finally the doctor suggested a very serious open lung biopsy.

Denton Regional Hospital (DRH), November 18, 2013 – 18 days

I got a second opinion from a doctor in Dallas so she had the evasive procedure and her situation only got worse. She called me at 0435 on the 26th of November and said she was dying. A week later with no positive progress the doctors decided her only choice was to go to Baylor for the big

surgery they had said a week before would kill her. After another bronc, she was put on the ventilator and in the ice storm we took her in an ambulance to Dallas on December 6th.

Big Baylor (BHC) December 6, 2013 – 45 days

After a week of determining if they would “support” her the decision was made to do the pulmonary thromboendarterectomy. She was *in extremis* (at the point of death) at this time but the surgery went well and after five and half hours and 33 staples she came out of recovery with a B+ from Dr. Alexis E. Shafee, MD. She opened her eyes on December 25th. She had a trach implant on December 26th and stuck her tongue out on command at the doctor the same day!

The good news from Dr. Graybill came on January 1 when he showed me the cat scan of her brain. She had a PEG bleeding delay of a week before we could move to rehab.

January 14th she lipped to both Kelly and I “I love you.”

Plano Specialty Hospital (PSH) January 21, 2014 – 28 days

A **black** day for the transfer as she was not on the vent but on CPAC.

A **black** day on February 1st as a nurse broke off a swab plastic tip in her trach so we spent the day in the Medical Center of Plano (MCP)...it was just &^%#! awful.

I started having people come and visit with her as her slowness in recovery both with the vent and waking up was really getting serious.

-----The next two weeks were just terrible as there was no positive progress-----

Seeing her talking to God early one morning was a gut wrenching experience for me

A **black** day on the 18th as it started off poorly at 0300, got better at 0730, and went to hell in a hand basket as she bit her tongue while having a seizure...then we went back to MCP at 12:58

Medical Center of Plano (MCP) February 18, 2014 – 8 days

Emergency room – six stitches in tongue, x-ray, meds, CT, ICU at about 1800, blood sugar to one and a big seizure that caused irreparable damage to her brain. EEG and MRI on 19th. Three days of EEG and four meds to fight the seizures with an MRI on 24th showing a global expansion spelled out the doom forecast – the options were not good. I asked for a second opinion. Then the Big meeting on the 24th and then the fateful day of the 25th – It was horrible.

Death is permanent but love is eternal

Selected events worth remembering (maybe)

* We stayed at the Baylor Plaza Hotel and during this time I got to really know my daughters. Dang, they are a lot like their mother – a bit headstrong at times and tend to say things I had heard at home. Any how, if there is any joy in the 99 days it was being able to spend some time with Kelly and Lisa.

* It would be easy to write a chapter on “Baylor Health Care Hospital: Sounds, Sights, and Smells”

* Do not go to a hospital and expect to rest.

* We will remember Lisa's blanket (seen at the service) that says "Grammy we love you!" And the Lamb of God – who carried us all through many a night of tears. I will remember Kelly singing to Jeanne "You are my Sunshine."

* It puts us to tears to remember the bruised, beaten, swollen body of Jeanne as she was put through the hoops with wires, tubes, connections, PEG, PICC, pipes, bags, hookups, cables, and all the rest. It was horrible.

* Everyone should put on the hospital garb and sit in an ICU for eight hours – to smell the roses, see the hundreds of people who go by, and listen to the thousands of bells, bongos, and whistles each hour. It was horrible.

* It was 515 steps from our hotel room to Jeanne's gurney/bed. Sometimes I would make five or six trips a day depending on the crisis of the hour.

* Code Blue has a new meaning to us now.

* Thank God for insurance.

Post script

Maybe one day I will see the glory...but not now. God won this one and I do not understand. At this moment I feel because Jeanne had really turned her life over to Jesus, as she said in a discussion a few months ago, she literally took up the cross and Jesus squired her smartly to her heavenly home.

There is some poetry here I am struggling with about the Gospel. We spend too much time in church listening to the songs about how Jesus died on the cross for us and singing how much He did for each and everyone of us – that now we can have heaven and eternal life. Perhaps it may not be that way. The gospel is too glamorized. "It is not success, but sacrifice! It's not a glamorous gospel, but a bloody gospel, a gory gospel, and a sacrificial gospel! Five minutes inside eternity and we will wish that we had sacrificed more, wept more, bled more, grieved more, loved more, prayed more, given more" (Leonard Ravenhill). "The cross is a death sentence to this world but a 'crossing over' to the world to come...it is of inestimable worth, a 'pearl of great price,' the true treasure of the heart, a joy unspeakable and full of God's glory."

Jeanne gave herself to God and God took her. She was crucified and this is the 99 day problem...

NO, there is more poetry:

So everyone (well, almost everyone) is telling me God knew. They tell me God knew before she was born how she was going to die. Well, I have a little problem with that. It is called the Problem of God. If God knows how all this is going to work out why should we do anything but just sit back and enjoy the trip? The suggestion of God being into so much control might fit into some sort of a predestination outlook but it goes against the preaching I hear about where you may end up in hell if you don't believe, don't go to church, and don't believe in the Bible - or whatever else one doesn't do. Seems to me there is an implicit choice in the matter. Do we have a choice or not?

I think God has less of a hand in things than what I hear everyone saying. Note: there are books written on this but my comments are to get me through why Jeanne spent 99 days in ICU and did not make it. Maybe God either has a lack in something comma like his power? Maybe we have a God who is in not in as much control of things as most people believe? Maybe we have a more caring God than we think. Maybe God cries too.

I say God cried for Jeanne. He cried just like we did. He doesn't just sit where He sits and watch the script go by as if it were already written. He is rather just as involved and concerned with the outcome as we are. We players are also just as interested and concerned with the outcome.

A script God wouldn't cry.

A script-less loving God cries (for whatever lack He has) because He does not pull strings. Therefore, some of us have to struggle, some of us have to suffer, some of us have only 9 days, and some have 99. Yes, God cries. He cried for Jeanne and hurt just like she did during her 99 days.

Yes, God cries because He cares.

My God is kneeling down with me and we are sharing our grieve over Jeanne, we are crying together over Jeanne who had some things happen to her during her illness and because of them she didn't make it. Some mistakes were made and she got the short end of the stick. My God and I are hurting because of the 99 days spent trying to get her well. It could have happened in 9 days but it didn't. Jeanne's suffering was real. It hurt her, it hurt me, it hurt my children, and it hurt God.

I should not be angry with my God who will cry with me. I should not be angry with my God who went through the 99 days feeling just like me and probably wondering why the recovery was taking so long. I should not be angry (again, an anaphoric referent) with my God who cares, who cries, who is as concerned about Jeanne as I am.

My sword is back in its sheath. My spear is parked. My Kimber is back in holster. I am ok now.

Epilogue

One night in late December in the ICU at Big Baylor I was talking to Jeanne while a nurse (Rachel) was doing something behind me on the computer. Actually, I was trying to get Jeanne to wake up and recover from her big surgery on the 13th. I was up close to her and being forceful with my hand kinda of beating on the end of the bed telling her she had to wake up. In my enthusiasm and trying to control the outcome I moved in and lightly kind of slapped her on the face – twice. "Jeanne," I said, "you have to wake up! You have to get well! We have to get out of here!"

I stood back - there was no "Biblical healing" and Rachel, who had moved in right behind me, said with tears in her eyes that Jeanne would be ok. She said God was going to take care of her. She added "And when Jeanne wakes up I am going to tell her that you slapped her face."

I pray for that day.

Finis coronat opus "The end crowns the work"