

June 4, 2021

Dear Praying family and friends,

EXECUTIVE SUMMARY:

On the morning of Day 3 of 6, I am feeling amazingly better than I ever have in the preceding month before arriving. No doubt I'm floating on a thick cloud of prayer. Thank you.

As to "mechanics" of how answered prayer is playing out, the present era of good feelings likely arises partly from the effects of high dose prednisone - side effects including feeling "up and at 'em" all the time, increased appetite served by amazingly tasty hospital food.

Medical personnel in [William P. Clements Jr. University Hospital](#) are excellent - skillful, polite, helpful, super-present when you call. For anything at all. My experience thus far strongly resembles a vacation, except for the attendant medical interruptions.

The telecommunications I heard hyped seem mostly to come from the marketing department, not the IT department. Pity that. Nice idea, poor follow through. But, I can still make video calls to Barbara via Zoom and my laptop.

The biggest blemish thus far seems endemic to the medical profession across the board - an almost reflexive condescension to questions and comments from patients concerning medical topics. I've had to get "up front and personal" with the daily Lymphoma Team Poobah, his attendants, the charge nurse, the pharmacy, the diabetic team. Things are better today, and hopefully also in future interactions. I had to surrender over-the-counter medications and also prescription medications that have been standard for me for over a decade. Now these have been returned to me on the condition that I do not use them.

A REVISED PLAN OF ACTION

I entered the hospital thinking that this intense week-long dosing with a stronger chemo cocktail was the totality of my treatment going forward. I was mistaken.

Whether it was a misunderstanding on my part, or a "hiding" of the playing of cards (see below) - the therapy plan now is more clear to me: *six to eight additional 6-day infusions*, followed by six to eight weeks of recuperation.

So, after I am discharged, I will be sent home for two weeks while blood counts and overall health is monitored. Then I will return for a second 6-day infusion, followed by another two-week recuperation, and so on for at least six cycles. Right now things are quite pleasant (!). I expect to feel less well after returning home. Our Lord knows.

WHEN/HOW TO ASSESS PROGRESS. OR NONE.

The physician doing rounds for the lymphoma team just departed. He confirms that I'm looking at six to eight of these 6-day infusions. This will, indeed, be a trek! After all infusions are finished, I will be taking oral chemo at home. Some time (hard to say when at this point), they will need to make an assessment as to how well the therapy is effective. One common evaluation tool is a second PET scan. But that's out there some months, so I'll bring that up when it's needed.

A WORD ON MEDICAL CONDESCENSION

First, my street cred comes from four sources - (1) a naturally curious mind concerning medical topics, trained by (2) a scientific undergraduate education in physics, chemistry, and mathematics, and (3) becoming a totally engaged heart-attack patient at the age of 48, and finally (4) serving as a patient-advocate for my daughter Francesca who was dying of a brainstem tumor. I did the same later for my mother dying of pancreatic cancer, and my father dying of end-stage heart disease.

In all these endeavors, I formed my opinions of medical service providers at ALL levels, and I also developed strategies for dealing with the worst characters in the medical service industry.

Second - medical service providers invariably think they hold *ALL THE CARDS* as far as their subject area is concerned. *Often this is true*. It was definitely true all the time 30 years ago. However, the advent of the internet has changed this. Oddly, though, modern medical service providers still think their knowledge is Olympian.

Third - as I said, because of the explosive growth of the internet, we ordinary folk have grown increasingly savvy about acquiring up-to-date information about research and therapies, medical procedures, and so on. This changes the relationship between physician and patient. The changes are sometimes rocky, and resistance to change comes *exclusively from medical service providers*.

The biggest problem for the patient is this: the medical service providers - the doctors, their assistants, the nurses - all of them do their jobs as if they have exclusive access to medical information, and we consumers have none. When the physician consults with the patient, he will lay only those cards on the table which he wants the patient to see. He will not tell an overt lie (that can ruin him in a malpractice suit!), but he can effectively tell a lie by withholding information which he does not wish the patient to know, or by failing to correct a patient's incorrect understanding of his own condition, his own prognosis, and so on.

So, an advocate for the patient is almost a necessity these days - someone to accompany the patient *everywhere*, a person who is free to take notes, to ask questions during interviews, and to counsel the patient on further investigations to be undertaken.

The most practical value of an advocate is to detect condescending BS and similar obfuscation on the part of the medical service provider. The patient must always say this when appropriate:

"I don't understand a thing you just said. Please explain again."

or

"You did not answer my question. Here it is again. Please answer it completely and in simple language."

And so on. It can feel like a tug-of-war. If you win, great. If you lose, you may need a different physician. I have run now into all this very situation in my current situation!

In one large cancer center back east, 30 percent of the elderly patients who undergo the very treatment I am at the present die during their treatment. My oncologist did not offer me this information. He did not even explain how very poor my prognosis is when we first discussed this treatment option. I was the one who learned from numerous research reports on the internet that the overall survival rate for my rare form of lymphoma is a mere five months post-diagnosis!

Fortunately, the National Institute of Health publishes on the internet a searchable journal, in which physicians and medical researchers speak to each other concerning all sorts of medical subjects. I went there and looked at the R-EPOCH chemo cocktail for chronic lymphocytic leukemia with Richter Transformation. I immediately learned that the prognosis is *very poor*. Sounds bleak, no? Did I hear a word of this from my oncologist? **No**.

So, in a phone conversation with him, I immediately said this: "I have been reading medical articles at the NIH on my condition and the chemo you're recommending. Everyone agrees that my prognosis is very poor. What do you say?"

If a phone voice can sound sheepish, his did.

"Well, Mr. Mouser, unfortunately, with your condition, there is very little we can offer at this time."

Two important things happened here - first, my question put him on notice that I was not one of those passive patients who would take spoon feeding and be happy with it. Second, his immediate (though belated) candor purchased for me an additional willingness to follow his suggestions for treatment and to press him in future if I wished to know something. For now, I feel hopeful that I can get him to lay more of his cards face-up on the table.

Enough of this for now. If we get to the stage where I am willing to participate in a clinical trial, I'll share my thoughts on this. My goal as a patient and a researcher's goal *are not the same!* They run parallel for a long way, but his aims and mine are different. More later on that, if it comes to that.

THANK YOU! REJOICE!

Friends and family, if we are in the Lord, we cannot lose! Nothing can separate us from the love of Christ. God knows the end from the beginning, and He has told us in His word that all ends well, forever well, for those who trust His son. Our Heavenly Father has shown us just how well that it is when He raised Our Lord from the dead and seated Him at His right hand. I cannot lose anything, nor can you if you are in Him.

Please pray that God's will for me and also for Barbara and my extended family of children, grandchildren, in-laws, and so on - that God's will for all these and my friends in the Lord is accomplished in all these things.

Expect another update toward the middle of June. I should know more about the next stage by then.

Much love in Him,

Fr. Bill