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## HOW THE COOKIE CRUMBLES: A PERSONAL HEALTH CARE EXPERIENCE

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“No man is a good doctor until he has been sick himself.” — *Old Chinese Proverb*

For a proper appreciation of what follows, I must set the scene for the hard lessons learned by a physician patient. I am an older (quite a bit) “respected, board-certified specialist in internal medicine and cardiovascular disease with over 50 years of clinical experience.” I like to think I’ve seen just about everything — but fortunately, until recently, I never had experienced a major medical encounter myself. Hip and knee replacements don’t count. So keep this in mind as you read on and as deficiencies in my medical acumen begin to unfold. There is a moral to this story!

For two years, I harbored a quiescent non-Hodgkin’s lymphoma sequestered in my abdomen and found quite by accident. Certain lymphomas have been known to smolder for extended periods and occasionally even to regress spontaneously. But when mine began to present lumps and bumps, my well-respected oncologist suggested 6 or 8 treatments at 3-week intervals of chemotherapy, euphemistically known as “CHOP.” (The name alone is ominous.) This, after a course of Rituxan 6 months earlier, had been only partly successful in slowing its progress. Although I consider myself reasonably informed on the subject of cancer in general, and the side effects of chemotherapy in particular, I did read several articles written for the laity that I found informative. My oncologist answered a few additional queries about side effects and prognosis. No detailed questioning — rather, just enough to satisfy me; as it turned out, not nearly enough to satisfy my wife and 3 sons.

So the intravenous therapy (IV) began without fanfare: Rituxan the first day, Cytosin, Adriamycin, and vincristin on the second, and an injection of Neulasta on the third to boost the white blood cell count. Oral prednisone was taken each day as well. This is the combination known as CHOP. I felt remarkably well the

first four days. Nausea was completely suppressed by large doses of antiemetics. By the fifth day, however, my appetite began to wane, my taste buds began to languish, and general malaise set in. Even water and Coca-Cola (my favorite soda) began tasting like gasoline. I stopped eating and drinking completely despite all prior admonitions. I lay in bed feeling awful. My mouth felt like a compost pile despite frequent use of prescribed mouthwash and teeth brushing. My concerned, anxious, and intelligent wife kept suggesting I call the doctor and report these symptoms. Sporadically, I would feel a little better and would therefore tough it out instead of calling him. Finally, when my skin hung like papyrus and urine ceased to flow, I gave in. When I reached him, he suggested I come in the next day for IV fluids. When my wife heard “next day,” she said “Not on your life. We’ll be there in 30 minutes — to stay.” And we were.

Settled in the hospital room with the IV started, I began to think there might really be a tomorrow. Then the oncologist arrived. His first remark was enlightening. “You don’t look so well.” But his second was downright demoralizing. After instructing me to “stick out my tongue” and finding a generous white plaque all over my tongue and throat, he said, “You have ‘thrush,’” a fungal invasion of the throat and mouth (*Candida albicans*) and a problem not unique in the immune-challenged. It must have taken him all of 60 seconds to diagnose my problem: that this “older, respected, board-certified physician with over 50 years of clinical experience who has seen nearly everything” and who has treated a good many patients with thrush himself had failed completely to recognize it in his own mouth. After some IV Diflucan and a nystatin swish and swallow, improvement was swift. I was back home in 48 hours. Recovering from the first chemo-

therapy round was thereafter rapid and complete. The other good news from this encounter was that my bone marrow was very responsive to the Neulasta; my white blood count peaked at 72,000 before settling back to normal.

When the next round of therapy came, I was ready. Antiemetics were on hand, swish and swallow and mouthwash used regularly, and allopurinol taken daily to ward off any renal calculi, sometimes a complication of CHOP. The 3-day IV routine was again uneventful, with no significant side effects until I began to lose my appetite and taste buds again on the fourth day, but again not unexpected. I was not concerned. On the sixth day, I went to work thinking things were not as bad as I had expected thus far. At about 10:00 a.m., a rumbling began in my abdomen reminiscent of a green apple “bellyache” for those of you who may ever have had one. When it showed no signs of improving, I decided I’d better drive home and get off my feet. I did, but to no avail. The discomfort became a real pain and settled in my lower left quadrant. This “older, respected, board-certified internist and cardiologist with over 50 years of experience who had seen nearly everything” decided he had diverticulitis, even though there had never been a suggestion of that problem in the past. Back to the hospital again, this time to the emergency room (ER) with son number one looking for more certain answers. In retrospect, I would have saved everyone a lot of trouble had I just called the oncologist then and headed straight for the ER.

In due time, I was seen by a resident, briefly examined, then had an ECG and venesection for laboratory studies. I also was seen briefly by a staff ER physician. All the while, the pain was intensifying in my left lower quadrant, waxing and waning but mostly waxing. A CT scan was ordered, in part because, among other things, I was known to have a small abdominal aortic aneurysm. I relaxed a bit. But the pain did not.

All the while, my number one son, a man with infinite patience, and I passed the time trying to solve the world’s problems — among them, the loss of blue crabs and oysters in the Chesapeake Bay due to pollution, and how best to fish the San Juan River in a snowstorm. All topics were at one time front and center in our lives. Eventually, I began looking for pain relief and asked about something injectable, like Demerol. I was informed that Demerol was no longer available in the ER. The choice now was Dilaudid. By then, several hours after admission to the ER, I was ready for anything. An IV of uncertain dosage was administered,

and within a few minutes the whole world turned rosy. If I ever have pain again, please give me Dilaudid. The pain waned, then disappeared and never returned. The urinalysis revealed the culprit: hematuria. I had passed a renal calculus. The CT scan revealed a remnant remaining in my left kidney. So much for prophylactic allopurinol. And so much for my diagnosis of diverticulitis.

With the pain abating, I began to concentrate on the delay in being admitted. I thought 5 hours in the ER was a bit much, and with my Dilaudid high, I found it easy to find fault. As a physician who frequented the ER often to see patients, I assumed it was perfectly acceptable — now that I was a patient myself — to straighten out all of the ER deficiencies perceived by my Dilaudid-induced deluded sensorium. After a testy discussion with the ER manager, I was sent to a room, accompanied by sighs of relief from those dedicated souls I had harassed for 5 hours. Poor exhausted son number one went home to a bracer, I imagine.

An overnight stay was followed by a trip back home after 2 units of red blood cells were administered to bolster a hemoglobin level of 7.5 g/dL. No special events followed the next 2 rounds of CHOP; just the usual malaise, bad taste (no thrush), easy fatigue, and a bundle of palpitations I attributed to one of the various CHOP ingredients. No one seemed to worry about them, so neither did I. Some of my cardiology friends at MD Anderson Cancer Center suggested I monitor my serum brain natriuretic peptide (BNP) as well as the echocardiogram to follow, particularly the effect of Adriamycin on the myocardium. They had observed a rise in BNP preceding a drop in the ejection fraction, so I followed their suggestion and found it to fluctuate between just above normal (under 100 pg/mL) and 650, elevated after a round of CHOP, then retreating before the next round.

Toward the end of round 4, I began to experience significant exertional dyspnea. On 2 occasions, orthopnea and paroxysmal nocturnal dyspnea occurred 3 weeks after the end of round 4. This “older, respected, board-certified specialist with over 50 years of clinical experience who had seen just about everything” decided the source of his symptoms was the chemotherapy, especially after an echocardiogram ordered by the oncologist showed an ejection fraction moving from a normal range after round 1 to around 25% after round 4, attributable in my mind to the Adriamycin. Of course, it never occurred to me that making judgments outside my area of expertise was foolhardy and dangerous. My oncologist, a wise man, knew better than to trust my judgments. I had

had no chest discomfort. I never seriously considered these symptoms might be secondary to other problems. Fortunately, the oncologist did.

A nuclear chemical stress test was wildly abnormal, followed shortly by a coronary angiogram with results that defied belief: severe 4-vessel coronary disease, including severe left main stenosis. I was prepared for some sort of bad news when the interventional cardiologist removed his gloves immediately after the procedure. No stent today. During the subsequent discussion with him and the surgeon and in the presence of my wife and 3 sons, I ventured the best course of treatment might be medical until I recovered from the chemotherapy effects and the anemia. And that I might do this at home, promising to stay off work for a week or two. The cardiologist looked at me without flinching and said, "If you leave the hospital, you'll die." No hesitation; no ifs, ands, or buts; no discussion. Conversation ended. Dead silence (pardon the pun). I then ventured, "A coronary artery bypass?" All heads nodded. "Before 7:30 a.m. tomorrow?" I asked. All agreed. For once in my life, I decided it was time to acknowledge the boundaries of my diagnostic and therapeutic skills.

I had not been correct at any time in the last 5 months when it came to interpreting my medical state. I, who was so sure of myself, so capable with so much experience, realized, finally, that when it came time to being a patient, it was time to be a patient and not a course director.

Accepting their advice has permitted me to write this memoir. Recovery from lymphoma therapy and a quadruple coronary artery bypass has been complete. My ejection fraction is now 60%. The hibernating or stunned myocardium has awakened. Looking back, I realize how much my health had deteriorated without my recognizing it. My world was crumbling, and I was not aware of it. A large dose of humble pie has been delivered, ingested, and digested. The crumbling cookie has been made whole. Unlike the legendary Humpty Dumpty, I have been put back together again ... with no thanks to my credentials. I've learned that even a "respected, board-certified specialist with over 50 years of clinical experience" has much to learn from being a patient. And the sooner we physicians all learn that from life, the better our patients will be served.