"No One is Exempt from Cancer": A Cancer Doctor’s New Lexicon as a Cancer Patient

These remarks were delivered by Michael A. Weiner, MD, professor of pediatrics, in June 2018 after he accepted the American Cancer Society’s Eugene D. O’Kelly Award, which honors the late CEO of KPMG for his commitment to community service and volunteerism. Dr. Weiner was recognized for his commitment as a pediatric oncologist and as founder of the Hope & Heroes Children’s Fund to support care for pediatric cancer and blood disorder patients at Columbia. His remarks have been condensed and are used with his permission.

By Michael Weiner, MD

I am honored, appreciative, and accept the Eugene O’Kelly award with gratitude and humility.

I have been a pediatric oncologist for more than 40 years, specializing in the care of children and adolescents with leukemia and lymphoma. I was a past chair of the Hodgkin’s Lymphoma Committee of the Children’s Oncology Group. I served as director of the Division of Pediatric Oncology and am currently vice chair for external affairs in the Department of Pediatrics. But, one of my proudest accomplishments has been founding the Hope & Heroes Children’s Fund that has raised more than $75 million to provide comprehensive, compassionate care, to enable innovative cutting-edge research, and to promote education.

However, tonight, I don’t want to talk about my experience as a doctor. I want to share with you something that recently consumed me. In February I was diagnosed with cancer when a biopsy of a nodule behind my right ear was diagnosed as a follicular lymphoma.

How ironic. I have spent my life devoted to and caring for patients and their families, but now there was a knock on my door and I had no choice but to let this unwelcome visitor into my life to write my next chapter. I am now a cancer patient. I joined a fraternity of almost 2 million people in the United States who are diagnosed with cancer each year. Frankly, it is a club that no one would choose to join.

Cancer is ubiquitous. It affects all people without discrimination. It afflicts the young and old; male and female; white, black, yellow, and brown; Christian, Muslim, Buddhist, or Jew; the wealthy and people who live in poverty. It is true that statistically some cancers are more prevalent in one group than another, but ultimately cancer represents the epitome of diversity.

To cope with my new reality I thought of the thousands of children and adolescents I have known and treated. I thought of their courage in the face of pain, and suffering, beyond comprehension. I thought of all the tests, procedures, surgeries, and treatment that they endured. I thought of the patients who tragically succumbed from their disease and I thought of the many survivors who today are not only doctors, lawyers, teachers, and business men and women, but also husbands, wives, and parents.

I developed a lexicon to help me navigate and define my experience: Disbelief, Acceptance, Trust, Isolation, Uncertainty, and Research.

Disbelief. Did this really happen? The question “Why me?” did not seem relevant and was a query I never asked. While it was difficult at first to wrap my mind around the concept of having cancer, I never questioned the diagnosis. Follicular lymphoma is not rare or unusual, thus I accepted it.

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I began the process of selecting a doctor to coordinate my care. I consulted many, but realized what was important to me was to find someone who would give me what I have strived to give my own patients. I did not require a doctor who has been declared the “best” or “biggest,” but rather I needed my doctor to be understanding, compassionate, available, knowledgeable, and willing to be my partner on my cancer journey. Jennifer Amengual and David Horowitz possess these qualities and I trusted them. My home is Columbia and NewYork-Presbyterian and I chose to receive my care there.

Although I was familiar with follicular lymphoma, like most patients I Googled the entity and read voraciously, lay articles and scientific papers. Although my doctors were optimistic, I was disheartened to learn that there was no universal treatment that leads to cure and there were no guarantees.

I do not believe that my path to cure would be a battle; the euphemism of going to war against cancer was not how I viewed the process. I considered the ordeal to be one of coexistence and I tried to create a calm, anti-cancer environment. I made lifestyle changes: meditation, acupuncture, exercise, and a healthier diet to complement immunotherapy and radiation treatments. I accepted cancer and chose to allow it to evolve, transform, and disintegrate.

I found that cancer patients are isolated. The well-meaning protestations of friends and colleagues such as “I am so sorry” or “Let me know if there is anything I can do to help” frankly did not resonate or make me feel better. I felt alone. I was alone while receiving Rituximab on the 14th floor of the Irving Pavilion. I felt alone while receiving radiotherapy in the basement of the old Presbyterian Hospital. Having cancer is a solitary experience.

Every patient with cancer faces an uncertain future and I believe my unanswered questions are not unique. Will I be able to continue to work and be productive? Will I see my children and grandchildren grow, and what will they become in our uncertain world? Will I fulfill my bucket list? Will my wife, Wynne, and I grow old together? Will I be a cancer survivor? I am hopeful that all these issues will be resolved in a positive manner and I will join the ever-growing cohort of cancer survivors.

Cancer survivorship is directly related to the last word in my glossary, research. It is research supported by organizations such as the American Cancer Society and the Hope & Heroes Children’s Fund that will make a difference. Research will allow me to be a survivor. Should the malignant monster knock on your door or the door of a family member or friend, it is research that will provide the cure. Cancer diagnostics, molecular biology, genomics, and personalized precision-driven treatment are transforming every aspect of oncology. But, the cost is great and we must all do what we can to support ongoing research.

No one is exempt from cancer; any one can become a member of the club. I would like to leave you with one final thought in the words of Dr. Roy Vagelos, a physician-scientist, business leader, and benefactor of the Vagelos College of Physicians and Surgeons at Columbia University: “All of the magic you see in medicine today is because of basic science.”

CODA

A Poem by Marilyn Heins’55

Monthly blood, sweat, and tears no longer flow from shrunken womb, drying sebaceous and lacrimal glands. The first accepted long years ago, deodorant swabbed from habit not need. But my tears are sorely missed. How strange to cry when cheeks stay dry! Age robbed me of the copious flow of tears that washed away most pain though never all. Memory of pains past float up and prove I am alive and sentient. Actuality of pain in joints and other body parts, is not welcome but can be borne. Life, still precious, is worth that price. A grandchild’s voice, a loving touch, the crescent moon, sounds of music and trickling water all attest to my grateful, beating heart.

Loss of hair and height considerable. Where have all those lustrous locks and more than two inches of me gone? I miss them as I miss my tears. Eyes and ears still present and accounted for but function only when assisted by glasses and costly little aids to help me hear. My brain still works given enough time. Lightning-fast neurotransmissions clogged by the molasses between synapses slows recall of names and mental maps. Yet still I cerebrate, an amazing human skill. Recalling a face or poem or fact from long ago brings joy. I remember, therefore I am. I forget, therefore who am I? An old lady.