

WALTER C. ALVAREZ AWARD ADDRESS

The Walter C. Alvarez Award is named in honor of Walter C. Alvarez, MD, a pioneer in the field of medical communication. The award is presented to either a member or nonmember of the American Medical Writers Association (AMWA) to honor excellence in communicating health care developments and concepts to the public. The Alvarez Award is presented during AMWA's Medical Writing & Communication Conference.

Every Person Is a Patient: Finding the Story in the Science

Mary Elizabeth Williams / Journalist and Author, *A Series of Catastrophes and Miracles: A True Story of Love, Science, and Cancer*

Hi, everybody. When I was first contacted by the American Medical Writers Association way back on February 18th and informed that I was the recipient of this year's Walter C. Alvarez Award, I was so excited and honored and surprised and immediately eager for the day when we could all be together. I ended my email, in fact, by saying, "I can't wait to see you."

It is very bittersweet to be with you today in this format, in my bedroom. Again, still, where I have spent so much time over the past several months looking at these 4 walls and that pile of laundry, right over there, that I will get to later.



I have changed. And I'm sure that you have changed as well. We've changed in ways that are unique to every single one of us and we have changed collectively. Some of those changes have revealed themselves very slowly over time and some of them have been quite abrupt.

I happen to know about both of those things, and so I thought maybe we could spend a little time today talking about that. Talking about those moments that define us and who we are. The ones that we see ourselves in terms of the before and the aftermath of. That first kiss, the loss of a parent, the birth of a child, an act of violence, a report on the news, a phone ringing in the middle of the night, or ringing in the middle of the morning.

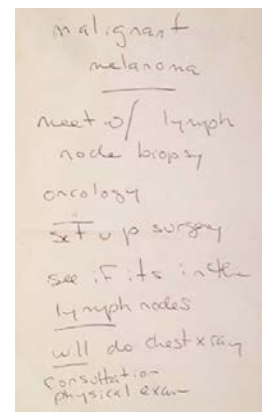
I'm going to tell you about the phone call that changed my life. This, as we say at the beginning of every comedy movie from the last 25 years or so, is me. Just a normal person on a

summer day, maybe a little bit of an overachiever, maybe a little bit of a type A, because what good comedy doesn't start with someone like that? Taking my first and what turned out to be my last trapeze lesson.

This is me, less than a week later, on another summer day. I don't think that I look very different, certainly not to a casual observer, although I see the changes. I see my older daughter, age 10, happy to have a day out, but I wonder what she was thinking. And I see my younger one, age 6, with her arms around me, and holding me protectively. And me holding her. I'm wearing a brand-new hat. It's ridiculous, and I don't like hats.

I see something inscrutable in my face because I look at the camera and I know that this might be my last summer. Let me take you back a few days. It was 10:30 in the morning, August 11th. I was on a deadline for a story and it was my dermatologist. I had been in her office a week before to have her look at a weird scab on my head. I had not been worried about it at all.

The first thing she said to me was "I'm so sorry." So, I grabbed a piece of paper and I started writing. *Malignant melanoma*, underlined. *Meet with* and then, nothing, because I think she said the doctor's name too quickly. *Lymph node biopsy*. I didn't really know at that point what lymph nodes are. I'm still a little unclear. I do, however, know that I am very ticklish when my lymph nodes are checked.



Hello, this is your life now.

Oncology, that is a word I do know, so I underlined it. *Set up surgery. See if it's in the lymph nodes.* To my everlasting shame I wrote *it's* without the contraction, and that is very unlike me. *Lymph* I underlined again, *will*, underlined, *do chest x-ray. Consultation, physical exam.*

At the end of that phone call, I was someone else. I was a patient. The following day, I met my brand-new oncologist because I was a person with an oncologist. And a few days after that, I had surgery. I had a couple of centimeters taken off the top of my head and with it the hair. I ever since have had a big old bald spot on the top of my head, and I have learned a lot about combovers.

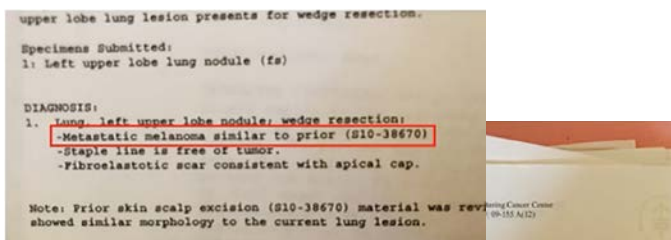
As you can see from this photograph, I also learned that if I thought my other hat was ridiculous, I was entering a whole new world of ridiculous hats.



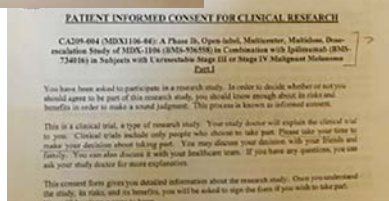
I recovered. I found out that people have a lot of opinions when you get sick. Some of them are very helpful, some of them are not. And I began yet another new life, this time, as a “cancer survivor.”

This was my life for a while. Three months to the day after I was diagnosed with cancer, my best friend was diagnosed with ovarian cancer. My father-in-law died of colon cancer. I went to the Rocky Mountains with a friend. I went to Orlando with my family, and we saw Hogwarts and drank butter beer and things were good, for a time.

So record scratch, a year after my first diagnosis, I was diagnosed again. There had been some troubling spots in my lungs. I didn't know that when I went in for my surgery that I already had a presumptive diagnosis of stage IV. I didn't know that diagnosis carried a presumed 7 more months to live or that my odds of surviving 5 years were well below 10%.



I hate sequels.



It was the beginning of the school year, and the likelihood that I was going to be around for the end of it was very slim. But I hit the jackpot. I became one of the first people in the world in a clinical trial for immunotherapy. I was one of the first 10.

I became one of the first people in that trial to present no evidence of disease. And yet, when I look at my informed-consent form, I see how little I understood. I understood maybe the word *melanoma* in that form. And as you can see, I put a question mark next to everything else.

That is unfortunate. It is unfortunate that the phrase *informed consent* rarely delivers on the first part, and then by consequence, it's very hard to get the second part. And I wish that that was different. And I believe that it can be, because we need to live in a world where information is clear, and consent is truly authentically possible.

I spent 2 years in my clinical trial. I spent a lot of time at the hospital. At one point, I had a nurse tell me she had never taken that much blood out of one person in a single draw. And I was doing all of this while I was still working and parenting and living my life. Because that's how it is. The experience of illness and treatment happens in our lives and our world. It does not occur on some separate plane in some other planet. And we are all seeing that in a very real way right now.

We have to have context for our conditions because they are not discreet, and they don't take place in a bubble.

These photographs were taken about 2 weeks apart.

[Editor's Note: Faces of two children in the photo on the right were blurred for privacy reasons]



You can probably guess the time of year. I took my daughters to meet Santa Claus and they asked me to come with them. I was really feeling the effects of my treatment at this point. It was pretty hard. And I was very tired. And my girls whispered something to Santa Claus, and when I asked my older daughter what they said, she told me, “I can't tell you or it won't come true.”

And then a little while later, my family and I were with our cancer support group, and my phone rang, and it was my doctor. I had had my first set of scans that morning, and he told

me that I presented no evidence of disease. And I asked him, “Now what does that mean?” And then he explained it to me, and then I cried. And I went downstairs, and I told my daughters. They were in the midst of a birthday celebration. It was one of the happiest moments in, I think, all of our lives. And I took that photograph. That’s the moment that my daughters learned that their mom was going to be around. And very shortly after that photograph was taken, the moms of the other 2 kids in that photograph died of cancer.

I have now been cancer-free for 8 years, but I am always a patient. And sometimes that is a real badge of honor, and sometimes I wish that people could see me as more than just a patient. My doctor and I used to do a guest lecture at a translational medicine class at a prestigious medical school every spring. And every spring, the physician who taught it would introduce my doctor by listing all of his achievements and experience, and then he would turn to me and say, “and a patient.”

I don’t think he ever bothered to learn my name. I don’t think he ever saw me as a human being with a story to tell. With an experience that informed the process of research. I think he saw me as cells on a slide. But I’m very fortunate because he was an exception.

Which brings us almost to the present. I took this picture in Madison, Wisconsin. I was on a work trip and I stopped in for lunch before my flight home. It was the last time I was in a bar. It was the last time I had a conversation with strangers sitting next to me. There were 2 coworkers who came in from across the street for their lunch break and started talking. I had the grilled cheese with caramelized onions and fig jam. And a beer. And if I had known that I would not be doing this again for a very long time, I would have had dessert. It was the last time I was on an airplane. My life and the world have been very different ever since.



And when I look at that photograph of a bunch of taps, I see something that is part of a health care story that is part of

the story of 2020 and the pandemic that changed everything. I think I got a little bit spoiled being in a clinical research trial. On the one hand, yeah, I was a medical experiment, and I didn’t know if I was going to live or die and I didn’t know if the treatment itself might kill me, but on the other hand, I got to be part of the process. I got to be a reporter, which is completely in my wheelhouse.

I worked with a team of doctors and nurses and researchers who for the most part respected me and listened to me. I was a collaborator. And an active voice in what eventually became the story of a treatment that has gone on to change how we look at cancer and has radically altered countless lives, not just for patients, but for their parents, their children, their spouses, their colleagues, their students. It’s amazing. And it is truly one of the most epic things that ever happened to me.

It also taught me that that is how it should be. I want to make it clear that I am not some Facebook mom who thinks that Googling makes me more educated than my doctors. What I am, though, is someone who has experienced what we all have in life, and particularly over the past few months, someone who knows that the medical world is the world that we live in.

That health care is not a place or a single experience or procedure. Sickness, wellness, maintenance, chronic illness, mental health—they take place everywhere, all the time. All day long. In the absolute thick of our work and our parenting and going to school and taking care of our aging parents and financial insecurity and loneliness and love and fear and hope.

I always bristle when I hear the phrase “clinical trial subject.” Because it implies that I was simply an object of study. And I was. But I was not just that. Being in that trial took effort. Being a patient takes effort. Walking around in a body every day takes effort. That is why I prefer the word “participant.”

And right now, we are all participants. There is not a person in the world who doesn’t know what it is like to be slingshot into a health care crisis. There isn’t a single person who hasn’t seen the profound inequities that we face, the challenges that are unique to the most vulnerable among us, and who has not seen and depended on in a new way the underappreciated and often invisible work of the people who truly keep this world running.

We need to be sensitive to that. We need to listen to that. We need to learn from that. We need to learn from each other. I’m so deeply honored and moved to be here with you, albeit virtually, in my bedroom. To be among people who have dedicated their careers to medical communication. I’m so impressed with you. I am so impressed with everything that you are doing to make sure that the science is translated accurately and clearly, especially right now in an age where there is so much misinformation competing for our attention. And it is a very confusing and disruptive time.

Lately, I have been studying in the field of medical humanities, and I have really been so edified to see that health care and humanities actually don't have to be in competition with each other. That we can hold the dialectic and that concepts like critical thinking and listening and simple language are essential to the process.

I know that humanities aren't as sexy as data, but they are not decorative. They are essential for our survival. I have a friend who is a researcher, and at the beginning of this, I called him, and I said, "Talk me down." And he said, "We're going to get through this. It's going to be a mess. But we're going to get through this."

I spoke to him again recently and I said, "I need a pep talk," and he told me about how over the past few months, even when spikes have been happening in different places and even when the news has been particularly grim, what he has seen have been the ways in which people have been adapting. The ways in which doctors and health care workers have been learning and the ways in which we all have been learning. We are all participating in the process of making a healthier and better world, every single one of us. And we're all learning from each other. We're learning what works. We're learning how to improve the system of communication and of care. And that

is what gives me hope in all of this. And that is not just about data. It is looking at people in context. Looking at the messiness and the imperfection of our lives. The pile of laundry I believe I have mentioned.

I hope that context gives a deep well of information and richness to diagnosis and treatment. When we see not just disease, but we see the people affected by it. When we see the circumstances. When we see—what better example than when we see preexisting conditions and we see the impact that they have on health care? Health care is not isolated. We are all our circumstances. We are all our stories. We're all patients. We're all participants. We're all people, first and foremost.

The only way through this is together. And the only way through this, as ever, is just by listening. So, thank you for listening to me today. Thank you for this award. Thank you for everything you do. I am so deeply appreciative.

Acknowledgment

I thank Elise Eller, PhD, Medical Writer and Consultant, Whitsell Innovations, Inc, for her help in bringing the transcript to the page.

***Author declaration and disclosures:** The author notes no commercial associations that may pose a conflict of interest in relation to this article.*

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