



**Life Stories**  
Individual Lives. Collective Impact.

SULEIKA JAOUAD INTERVIEW  
*THE THREAD SEASON TWO*

**Suleika Jaouad, Writer**  
**January 19, 2023**  
**Interviewed by: Nancy Steiner**  
**Total Running Time: 28 min and 2 seconds**

START TC: 00:00:00:00

ON SCREEN TEXT:

Life Stories Presents

SULEIKA JAOUAD:

My life imploded pretty much overnight with the news of my diagnosis. I lost my job. I lost my apartment. But maybe worst of all, I lost my independence and my sense of possibility. I felt profoundly stuck.

ON SCREEN TEXT:

The Thread

Suleika Jaouad

Writer

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SULEIKA JAOUAD:

So Jon Batiste is my husband, my longtime friend. And of course, I'm biased here, but an extraordinary musician, thinker, composer. He was raised in New Orleans and hailed from, you know, several generations of musicians. And we met at 13 years old, at band camp in upstate New York,

which set us off on a trajectory that I am certain neither of us would ever have imagined, would end in marriage. But here we are.

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INTERVIEWER:

And can you just tell me a little bit about that story, how that happened, that you found each other?

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SULEIKA JAOUAD:

So we met very briefly at this music camp. But like all summer camps, you don't necessarily expect to see each other again. And it was a couple of years later when I was 16, and I had just been admitted to the pre-college Juilliard program, and I was on the 1 train with my friend Michelle going up to Juilliard's campus, and we saw this young man, and everyone was sort of staring at him in the subway car, because he was playing air piano and singing to himself and attracting a lot of attention. And I took a look at him, and I turned to my friend and I said, "Oh, that's Jon Batiste from New Orleans. I know him." And then I blurted out in a very sort of impulsive 16 year old way, "That's the man I'm going to marry someday." Completely forgot about it. But as it turned out, Jon was also a student at Juilliard, and we kindled a long friendship and kept orbiting in and out of each other's worlds.

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SULEIKA JAOUAD:

But it wasn't until I turned 22 and learned that I was sick with leukemia, that our friendship really deepened. The first day Jon heard that I was sick

and that I had been in the hospital at Mount Sinai for several weeks at that point, he brought his entire band. They were mid rehearsal, to the hospital and put on an impromptu concert right there in my hospital room. And as the sound of music filtered into the hallway, patients and doctors and nurses started to come out, and all of a sudden everybody began to sing and to dance and to laugh together. And it was this rare moment of exhale and joy in a space that we don't typically associate with joy. But it was also my first indication of a quality that Jon may not be publicly famous for, but one that I treasure so deeply, which is his ability to show up in the hardest moments, and to lead with this deep sense of love and community, and using music and art as a way to bring people together.

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INTERVIEWER:

What happened when you were 22? I know that you had gone through all of this period of itching intensely and being told, you know, oh, it's nothing serious. You're itching. And then finally you receive this betrayal of your what you assume to be your life story.

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SULEIKA JAOUAD:

What began as an itch my senior year of college morphed into a marrow deep sense of fatigue, and just constant bouts of bronchitis and colds and all kinds of things. And it was my first indication that one of the biggest challenges of being sick is learning to advocate for yourself and being believed. It took over a year for me to get an actual diagnosis, and by the time I did, I was diagnosed with myelodysplastic syndrome, which had turned into acute myeloid leukemia. And I was given a prognosis of about



a 35% chance of long term survival. And this news hit me like a closed fist to the face.

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SULEIKA JAOUAD:

Overnight, my whole world imploded. You know, to get sick, especially with an aggressive form of cancer at 22, felt like a breach of contract with the natural order of things. I was watching my friends traveling the world and launching into their careers, and going to parties and all the other small and big milestones of early adulthood. I moved back into my childhood bedroom in upstate New York and shortly thereafter entered the hospital to begin what would end up being a four year course of chemotherapy, clinical trials and eventually a lifesaving bone marrow transplant. But it was really one of those moments in a life that creates a fracture.

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SULEIKA JAOUAD:

There's your life before and everything that happens after. But I think the biggest thing that came with that diagnosis was a shift in my relationship to time. Especially when you're 22, there's this sense of endless time, time to figure out who you are, time to figure out what you want to do and what you want to contribute to the world. And with the news of this diagnosis and what happened after, I became acutely aware of my finitude, and that in fact, we don't have lots of time. Life goes by in a flash. As the great Joan Didion said, life can also change in an ordinary instant. And so it was a brutal lesson to learn that young and in some ways, a really clarifying one.



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INTERVIEWER:

You had lived an essentially normal life before you had cancer. How did you grow up?

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SULEIKA JAOUAD:

I grew up in a family of misfits. My father's from Tunisia, my mother is from Switzerland. I moved about 12 times on three different continents by the age of 12. And for a lot of kids, you know, you don't want to stand out. You want to blend in. But I had to learn early on how to be a sort of anthropologist in the world, how to negotiate my family's culture at home, my parents respective cultures, and the one of whichever place we were living in. And so, in a sense, I feel like my childhood prepared me to be a writer, to be an observer, to pay attention to the world and the people in it, and the distance between me and them.

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SULEIKA JAOUAD:

Our house's premium was on books and art and theater. And that was what my parents cared about, and that's what they wanted to bring to us. So we grew up with no TV, no video games, but a very large library. And while my parents were strict about other things, we were allowed to read anything that we wanted as long as it grabbed our curiosity. And so I think from an early age, it was inculcated in me that creative pursuits weren't something frivolous, they were something crucial and important to how we understand the world, and even how we can begin to enact change, however small that may have been.



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INTERVIEWER:

What was pre-cancer Suleika all about? What mattered to you most? What excited you before your illness?

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SULEIKA JAOUAD:

The central image that comes to mind when I think back to pre-cancer Suleika, as a young woman barreling down the dock and diving headfirst without looking, without caring what's below the surface into whatever it was that was pulling me. I was full of passion. I was full of ambition. I couldn't wait to begin my life when I graduated from college, and I had dreams of becoming a war correspondent. For whatever reason, I, you know, from the time I was very little was missing that fear gene that when there's a crisis tells you to step away. And my instinct was to hurtle toward it. And so I wanted to become a journalist. I had always loved writing, but I felt that, you know, the idea of being a writer wasn't something accessible to me. It didn't seem practical. And I wasn't quite sure how to even begin to get my foot in the door. And so journalism seemed like an alternative that relatively, you know, seemed a little easier to penetrate.

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INTERVIEWER:

How did you decide to write about your cancer?

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SULEIKA JAOUAD:



It never occurred to me to write about my own illness. I had no interest in becoming the sick girl and too closely identifying myself with that descriptor. But what happened was that in those first couple of months in the hospital, I got to a really low down place. I felt a deep sense of defeat as all the standard chemotherapy treatments weren't working for me. I felt a sense of social isolation, and I was really struggling to figure out how to find purpose in the pain, and this new reality that I was living in. And a friend came up with the idea of doing something called a 100 day project. And the premise was really simple. We were each going to do one creative act every day for 100 days.

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SULEIKA JAOUAD:

And for my 100 day project, I decided to keep the barrier to entry really low because I didn't want to set myself up for more defeat. I wanted to pick something manageable, something that I could see through. And so I decided to keep a journal. I have been keeping journals from the time I was old enough to hold a pen, and something interesting happened in the course of those 100 days of writing daily in that journal. And it's that I began to use the journal as a kind of reporter's pad. I found myself, you know, recording overheard conversations by the nurse's station. I was writing about the fellow patients I was meeting and my neighbor down the hall who was staging a hunger strike because the meal trays kept arriving with the food still frozen. I was writing about the unexpected moments of humor.

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SULEIKA JAOUAD:



I was writing about the things I couldn't talk about with my family and friends. The feeling of being a burden that can accompany the experience of being sick, the experience of staring your own mortality straight in the eyes. The things that felt embarrassing, like infertility, or the social awkwardness of being sick at such a young age. And the irony was that during that 100 day period, I could barely speak and yet, in the privacy of my journal, for the first time in my life, I felt like I was finally finding my voice. And so I decided to do what every good millennial in 2010 did, which was to start a blog. And I took this blog very seriously. I wrote in it every day.

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SULEIKA JAOUAD:

But I was using the source material from that journal to begin to explore a kind of first person writing that lives in that blurred boundary between memoir and journalism. And a few weeks later, I received an email and then a phone call from an editor at the New York Times asking me if I might be interested in writing an essay for the paper. And I took a deep breath, and I thanked her profusely, and then I said, "No. But what I am interested in doing is writing a weekly column about the experience of illness and youth." And I went on and on and on. Now, mind you, I had never been published before, and all of this would have seemed incredibly presumptuous to pre diagnosis 22 year old me, who would have been very grateful for...

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SULEIKA JAOUAD:





A fact checking position or an internship at a place like the New York Times. But in this weird way, I think cancer had made me brazen. And because I was keenly aware of my prognosis of how limited my time might be, I did what I had never done before in my life, and I simply asked for what I wanted. So I spent several years writing, "Life, Interrupted," the column.

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INTERVIEWER:

From that was Born Between Two Kingdoms. How did you decide to write the book?

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SULEIKA JAOUAD:

When I finally finished treatment, I was desperate to shed the skin of the cancer patient. I wanted to move on with my life. I wanted to quickly and seamlessly find my place back among the living. But to my surprise, that didn't happen, and I knew that the whole point of having endured what I had endured was to not only live a good life, but hopefully a meaningful one, a happy one. Otherwise, what had been the point? And so I had a really important early conversation, with the writer Cheryl Strayed, who's become a mentor to me. And I remember saying to her, "I want to write a book, but whatever it is that I write about, I don't want to write about illness. I want to move on from that. I'm done with that. I don't want to talk about it anymore."

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SULEIKA JAOUAD:



And she turned to me and said, "The funny thing about that is when I went to write *Wild*," you know, her mega bestselling memoir. "I told myself, whatever it is that I write about next, I don't want to write about my dead mother." And of course, the book is about her hike on the Pacific Crest Trail, but it's also about grieving her dead mother. And what I took away from that was that when you have a question, when there's a topic that keeps kind of beating at the edges or knocking at the edges of your mind, you have to write through it. You have no business ignoring it. And so what emerged from this season was my first book, *Between Two Kingdoms*, which is about that very experience of figuring out how to move forward from an experience like cancer, in my case. And really an investigation into how we carry what lingers, which for me were these visible and invisible imprints.

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INTERVIEWER:

Your artwork that you created when you were sick. You hadn't picked up a paintbrush since you were much younger. What took you there?

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SULEIKA JAOUAD:

So after nearly a decade of being in remission, I learned a year and a half ago, or almost two years ago now, that my leukemia had returned. And what followed was much of the same as the first time around. A sort of whirlwind shift in every aspect of my life. And I found myself back in the same hospital, back on the same floor with the same nurses, undergoing a second bone marrow transplant. And I spent about six weeks in the hospital. And during that time, I was put on a medication that caused my



vision to blur and double. And for the first time in my life, I couldn't reach for the thing that I love most, which is writing and the tools that I had built to help see me through difficult passages like the journal, were not really available to me.

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SULEIKA JAOUAD:

And so, rather than trying in a very frustrating way to do the thing that had worked for me once before, I tried to stay open to new things that might emerge. And one day my friend brought me some watercolors and some beautiful paper, and I picked up a paintbrush, which I hadn't done from the time that I was very, very young child. And I began to transcribe the fever dreams that I was having, the nightmares. And I discovered this whole new creative language that felt so freeing, in part because I had no expectation of being any good at it or of doing anything with it. It was a gift that I had access to that was purely for myself. And because of the medium itself. Watercolors are difficult to control.

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SULEIKA JAOUAD:

Part of their beauty is the loss of control and the way the paint blurs on the paper. And it felt like an apt metaphor, for what was going on in my life. And so by the end of those six weeks, I had plastered the walls of my hospital room with these sort of biblical fever dream, nightmarish self-portraits, and I emerged with yet another example of how creativity really is this powerful way of alchemizing whatever circumstance you might find yourself in and transforming it into something interesting and useful and even meaningful.

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INTERVIEWER:

When you received the second diagnosis and discovered you are going to have to have another bone marrow transplant. You're being asked to like take this plunge, and your partner at the same time, he's being heralded with 11 Grammy nominations. So you're having these sort of polarized moments in your lives. It must have felt really difficult.

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SULEIKA JAOUAD:

So the first week that I learned the leukemia had returned and that I began chemo, Jon was nominated for a historic record number of Grammys. And it was so interesting because, you know, you might think that I would have felt resentment in that moment. But the truth is that I have watched Jon work so hard from the time he was a little boy toward a moment like this, and I wanted him to be able to have it. And he-- his reaction was the complete opposite, which was, "I want to be here. I don't care about any of that stuff. I want to be in your hospital room. I want to sleep on the hospital couch every single night." But again, having gone through this before, I knew the cost of caregiving. I knew how long an illness like this can carry on.

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SULEIKA JAOUAD:

And as much as people want to be there 24/7 in the early months, this is a long process. And so I wanted him to, of course, be by my side, but I wanted him to seize that moment, to go out there and enjoy and savor all



the good that was happening, and to come home and tell me about it, because this was a win not just for him, but for the two of us. And we have, you know, both supported each other and worked so hard in our respective creative endeavors. But it's really been a family operation. And so it didn't feel like, you're going out here and I'm sitting here. It felt like an us decision. And on the eve of my bone marrow transplant, we cemented that by having a very impromptu wedding in the living room of our house.

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SULEIKA JAOUAD:

With bread ties for rings and just a very tiny group of friends who joined us because, as Jon said, we had a plan and this recurrence was not going to get in the way of that plan. I think the truth is that regardless of whether you're an artist or a writer or you don't consider yourself creative at all, we're all deeply creative. And in that way, survival very much becomes a creative act. You have to find new ways of keeping in touch with your beloveds, new ways of reimagining your limitations, new ways of finding places where you feel grounded. Even if that's in the confines of your bed.

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INTERVIEWER:

I've read that you're going through a time of rebirth, as though you've shed an old skin. Can you tell me more about that?

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SULEIKA JAOUAD:



So, on day 100 post the second bone marrow transplant, I had a meeting with my oncologist where he explained to me that while my leukemia was currently in remission, I was going to have to stay in some form of treatment or another for the rest of my life, in order to hopefully keep it at bay. And I started to cry in that moment, and he asked me what was wrong, and I said it was the word indefinite. That, you know, it felt possible to endure anything if there was an end date in sight. But the ongoingness of this experience felt really difficult for me to wrap my mind around. And he said to me, which is the thing that people often say in situations like this, that I needed to live every day as if it were my last.

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SULEIKA JAOUAD:

And I knew what he meant, but it filled me with a sense of panic. And I've come to believe that we should not live every day as if it's our last. If we were to all live every day as if it were our last, we'd be robbing banks and eating ungodly amounts of ice cream and, you know, cheating on our spouses or whatever it might be. But it puts us in this frame of mind of seizing as much as we can out of every day, out of every moment, in this place of taking. And so instead, I've had to figure out a different way of navigating this uncertainty, this heightened sense of uncertainty that I'm living with.

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SULEIKA JAOUAD:

And I've decided that instead, I'd like to live every day as if it's my first, to wake up with a sense of wonder and curiosity and awe that a newborn baby might. And when I do that, I'm focused less on wringing as much



meaning as I can and more on giving and what I have to give to the people around me, what I have to give to my work, what I have to give to my body to keep it nourished and grounded. And it has felt like a rebirth, as I'm emerging from this season of more acute illness, and slowly starting to find my sea legs.

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