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North Africa - West Asia - Connecting Resistances

On Illness

When bodies can fight no more

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Yara Sallam Photo: Rawya Sadek

Even the Finest of Warriors was published last year, and little did I know at the time the level of stress that my body endured in the process. I wrote the book to discover answers about burnout among women human rights defenders, to unpack questions of wellbeing, and to disentangle feelings of guilt from activism. I wrote it for my own sake, because I was sick and tired of feeling alone in my burnout. Maybe at the time of publication my cells were sick and tired, too. I am grateful, though, that when my cells decided to go nuts, they gave me a sign.

Yara Sallam is an Egyptian feminist and a legal researcher based in Egypt. She has worked with various organizations including the Egyptian Initiative for Personal Rights (EIPR), Nazra for Feminist Studies, and the African Commission on Human and Peoples' Rights (ACHPR) on diverse issues such as criminal justice, regional and international human rights mechanisms, transitional justice, freedom of religion and belief, and women human rights defenders.

In 2020, a few months before turning 35, I was diagnosed with breast cancer. Some months earlier, my father had been diagnosed with lung cancer. As soon as I learned of his diagnosis, I knew that I too would fall sick with the same illness. Six months later I felt a big lump in my breast, and tests later showed that it was indeed cancer. Since then, I have found myself thinking a lot about Sunila Abeysekera, an inspiring Sri Lankan human rights defender who died of cancer a few years back, and about Gabor Maté's video on the relationship between stress and disease. *Dis-ease*. The video keeps playing in my head as I develop a strategy to keep my cancer from coming back. *Dis-ease*.

When I got my diagnosis wellbeing became a question of life and death, not only a matter of privileged intellectual discussion. As I reflect now on the past few months— on my own treatment plan, the death of my father, and my struggle to concentrate on anything that I used to do before my illness showed up—I wonder how I might treat my body better to keep illness away. If I were to write *Even the Finest of Warriors* now, maybe I would write more about how our bodies are more fragile than we think. I would write about the choices we make that add stressors on our immune system. I would write about the relationships we have that make us feel trapped in our own bodies. And I would write about signs, especially the signs to stop.

Right now, I am back to asking the very first question that I asked when writing my book: *Why do we become involved in the public space and engage in activism*? I have spent the last year unpacking why, 20 years ago, I became interested in public activism. Was it because of my parents' interest? Did I want to earn their approval and their pride? How much of my choices were really my choices and how much was just me flowing like water as the river carried me in a certain direction? I do not think I have found complete answers to my questions.

Was I putting my body in dis-ease by the choices I made and the life I led? What did the clashes in Mohamed Mahmoud do to my body? The repetitive cycles of burnout at work? What about the feelings of anger and loss towards the revolution? And what about my father's illness, which brought my nightmare and fear of loss right before my eyes? Was it possible to have avoided them all?

Make no mistake, I do not assume responsibility for getting cancer. I am only trying to unpack what it means to respond to my dis-ease in a responsible manner. I did not choose to be ill or in dis-ease. Actually, all of the questions above speak to structural conditions that shaped my life and the lives of many others who want to make change in similar circumstances. Even if I had chosen another field of work, I would not have been able to escape being part of the 2011 revolution or the crushing events that followed. Going forward, I could choose not to take testimonies from human rights victims, but how can I possibly escape Egypt while wanting to remain in it? Reducing the amount of stress that made me susceptible to dis-ease is going to require some radical decisions about how my activism can become informed by my body's boundaries.

What about suppressing my emotions in prison? For my own safety and the emotional safety of others, I felt the need to mask my feelings, so I hid them and showed little of what I really felt for the 15 months I spent in jail. You do not have much of a choice when you are in the lion's den. It did not feel safe then to wear my heart on my sleeve.

I remember a dear friend reminding me of the power of disappointment. Looking again at my book, I remember that I had wanted to find *pleasure* in the midst of it all. Engaging in activism was also pleasurable and fulfilling. I found and still find meaning in living the life I chose, and I cannot pretend otherwise. The euphoria, comradeship, love found, and strangers' compassion. It was all worth it. Until I got cancer. Then the entire idea of pleasure became far-fetched.

I feel a distance between what I published last year and how I feel about it now. After my diagnosis, all of my senses became alert and my body switched into fight mode. Everyone and everything in my life was fighting my cancer cells: my food, doctors, homeopathy, medication, and radiation. I was no longer able to really laugh and I began to feel very conscious of my facial expressions, as if they were heavy. A friend helped me put a name to it: dissociation. I was laughing as if I were a marionette and someone was pulling the strings of my facial expressions. It was unnatural for me to laugh or to have a relaxed, happy face. But I kept performing because I did not want to worry my audience.

Since pleasure was out of the question, I had to find something else—not to support me in my activism, but to help me on my healing journey, which despite being relatively short, felt so long. I was privileged to have found an abundance of love. "Activate your support network", my therapist had said. And I did. In response, I found love, friendship, and generous care. I believe we can count on these things when finding pleasure is too difficult of a task while engaging in the public space. However, I acknowledge that this is not to be taken for granted, as for many it takes a lot of work to create and activate such a support network. As Pam Labib explains in her article, "[m]y life depends on a support network that has taken decades to create."

When I finished the cancer treatment protocol at the hospital, I felt like I had been set free after being imprisoned. It is strange to think about it as imprisonment, as it was outside of actual prison—do I mean "confinement" then? I felt *entrapped* in all that I have seen and been through in the last few years. Not only did I feel the weight of my work overburdening my body and putting it in a state of dis-ease, I also felt the weight of what I had witnessed in the revolution, my prison time, and my father's illness. I felt stuck in an old pattern of chasing love.

How I felt is not unique. Many activists feel the same way. I believe I got sick because my body could no longer handle it all. I went through all of the possible scenarios for why I got breast cancer and I am not convinced that I was especially genetically prone. I believe it was more related to the environment(s) in which my body was moving. No one can really tell why my cells decided to go nuts, but what I do know is that I no longer want to lead the same kind of life. I feel I owe it to my body to give it a chance to stay cancer-free, knowing that there are no guarantees. My partner told me, "Don't think about recurrence, your chances of getting it again are equal to your chances of getting it in the first place."

So, I have decided *to make healing my life project*. I realized that I no longer want what brought me to this point in life. I decided to leave Cairo, a step I had been delaying for different reasons, to go live in the countryside. Recalling the African Feminist Charter, I decided to believe that I have the "right to healthy, mutually respectful and fulfilling personal relationships". I drew boundaries and made decisions about the relationships in my life that have made me feel stuck. I decided that I will no longer tailor myself to be someone's friend. I will not suppress my emotions but work on respecting them.

I have always struggled with setting boundaries in my life, both in my personal life and in my relationship with work and activism. The lines have always been blurry, with much of my self-worth and feelings of deserving at stake. But I remember the difficult conversations with my therapist and think they were all necessary for me to reach the point at which I am today. Today, I am better at acknowledging my limits and honouring them. I have also learned through cancer that suppressing my emotions will only hurt me, literally, from the inside. So, I have decided to embark on a journey to accept my "good" and "bad" feelings, and to find ways to express them both. I still struggle with all of this, but I feel things are clearer in my head now.

My healing journey needed me to do what I felt I needed to do for myself, not for others. For the first time, I am putting myself first. And while I almost feel guilty for closing past chapters, I am enjoying the transition. This is not to overlook the sense of healing that comes from caring for loved ones—it is a privilege and a blessing to be able to be there for people you love. I believe healing happens in supportive fulfilling relationships of all kinds. Yet, it is important not to lose one's sense of self while caring for others. Priorities shift and while sometimes others can be a priority due to specific circumstances, it should not be the norm.

My ability to make better decisions for my overall health has been hugely helped by the fact that I work for a human rights organization (EIPR) that has been very supportive throughout. An important element of the transition in my healing journey has also been to stop being in the "waiting room"—other people's waiting rooms and my own. I finally decided to leave *al-Qahera*.

It feels like cooking. My "recipe" consists of reducing city stressors, pollution, and junk food. It involves adding things like getting better at navigating personal boundaries, accepting life's gifts, and believing I deserve a good life despite the ugliness surrounding me. I deserve to be healthy, happy, and loved. Everyone does. But I also know that reducing stressors is a privilege; everyone cannot just wake up and change their location or their jobs. For me, it is possible because of years of therapy, investments in my work and in relationships that have paid off, and a strong dose of pure luck.

For years, I was unable to make the decisions I am making now, though they were always goals towards which I aimed. During my individual healing journey, I have learned to find different ways of responding to stress, and learned that this can be a worthwhile mid-term goal all on its own.