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REFLECTIONS

Negotiating illness — anchored in solidarity and collective healing

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Abstract

This essay traces my journey through my breast cancer diagnosis and treatment, and the effects on my body, identity, and daily life. While medical treatment shaped the clinical arc of illness, what sustained me was the care and support of family, friends, peers, and unexpected allies. This network, embodying the ethics of care rooted in reciprocity, solidarity, plurality, and compassion, expanded my agency. My narrative also reflects briefly on the structural inequities of cancer care in India and challenges conventional metaphors of illness, offering instead an ethic of reconciliation and collective healing.

Keywords: *breast cancer, care, solidarity, reconciliation*

When I was diagnosed with a tumour in my right breast seven months ago, my world narrowed abruptly. Overnight, my life started revolving entirely around hospitals. The sharp smell of disinfectant, the cold gel on my body in the labs, the sounds of machines, and the long stretches of waiting seemed to pause time itself. I grew familiar with medical terms like Tru-Cut and sentinel node biopsy, biomarker, targeted therapy, to name a few. I found myself learning a language which was never meant to be part of my daily vocabulary, yet it became the medium through which my days unfolded.

Diagnosis and disorientation

My diagnosis of HER2-positive breast cancer set me on a course of chemotherapy, targeted therapy, surgery, and radiation. Chemotherapy was harsher than I had anticipated. Many side effects were unlisted and normalised, yet profoundly debilitating. Physical exhaustion was only one layer. Beneath it ran a steady current of anxiety, fear, uncertainty, along with the stress of managing treatment within the limits of time, finances, and daily life. Illness is never only biological. It disrupts the emotional, social, and economic structures that hold one's life together.

The "Outsider"

To make sense of this sudden disruption, I found myself creating a distance from my experience. This distance wasn't detachment, but a kind of dissociation — observing my thoughts and reactions unfold as if they belonged to someone else. I felt like an outsider in my own life, living through the illness and simultaneously observing myself, both as subject and witness. This dual awareness helped me comprehend a world that had turned upside down far too suddenly. This estrangement was not only emotional; it emerged from the way illness redraws the boundaries of selfhood.

Breast cancer—its diagnosis, treatment, and medicalised vocabulary, imposed a new storyline on my life, forcing everything to be rearranged around this new narrative. Through my health research and advocacy with marginalised communities, I had long understood that illness is shaped not only by biology but also by the systems, institutions, and market forces that determine how bodies are classified, treated, and valued. Yet experiencing this reality through my own body made that familiar truth immediate and deeply embodied.

At times, my body felt like a set of disconnected, individualised parts. Medical procedures focused so intensely on removing the tumour that the rest of me seemed invisible. The effects of the treatment on my fatigued body as a whole, my confusion and grief, and my exhausted mental state were often overlooked in clinical assessments. This narrow medical gaze missed how illness affected my daily life, mood, and sense of self. It also obscured my sense of agency, reducing my body to a site of intervention rather than a living entity with its own knowledge and needs.

Family and friends

In the midst of this disorienting landscape, my family held me with remarkable steadiness. My partner anchored me when everything felt precarious, accompanying me through every stage of the illness—visiting hospitals, absorbing the doctor's words, and quietly holding my fears when they felt too large for me to carry. What I often could not see in those moments was his own fear: the uncertainty, the late-night worry, the careful composure he maintained — so I would not unravel.

My daughter and son were deeply shaken by the news of my cancer — a word that evokes its own quiet, overwhelming fear. They were worried and cried quietly, trying to comfort each other, even as they struggled to understand what was happening. They waited anxiously for every scan and test result. The diagnosis felt so sudden and unexpected that they slipped in and out of denial, checking with friends and trying to make sense of this new reality.

Alongside them stood the rest of my family, even those living far away. From the moment of my diagnosis, my brother rushed to be by my side, supporting me emotionally through those initial unsettled days. My sister-in-law and nieces visited regularly, ensuring we were not alone and helping with the practicalities of caregiving. My sister and brother-in-law, and nephews – though unable to visit often, were equally concerned. And while we worried about the high costs of treatment, my family reassured us, saying, *"Treatment first, costs later. Let us not delay."*

My 85-year-old aunt offered unwavering support, checking on me regularly, while my 92-year-old *khala* sent daily *duas* (blessings), grounding me with confidence and comforting me with their own experiences of living through breast cancer. Their constancy eased the isolation of illness, reminding me that the body never suffers alone; it exists within relationships that bear witness to, and sometimes absorb, its pain.

A web of care

My friends, like my family, became my lifeline. They wove a web of care— practical, emotional, and humane. When the news of my diagnosis broke, many were deeply disturbed, struggling with their own fear of what this meant for me, yet ready to stand beside me. They quickly created a WhatsApp support group to stay updated, coordinate with each other, and build a roster for hospital visits, so the burden on my family would ease. They organised transport, accompanied me to hospitals, brought headscarves, and sent food I could actually eat. When the pain from cannulas pierced through my thin veins, they sat beside me—sometimes holding my hand in quiet solidarity, sometimes reading poetry or playing music to distract me from the pain. They helped me reclaim small moments of normalcy and reminded me that I was not walking this road alone. These gestures of quiet solidarity were a reminder that care extends beyond bloodlines or kinship.

Friends even offered to step in and take on parts of my work in the organisation I was associated with, so that I could focus on treatment and recovery without worrying that everything would fall apart in my absence. Friends from afar kept sending messages of love and support, books, and music — gestures that held me in ways where distance did not matter. Some offered financial help, gently challenging my instinct to manage everything alone. A couple of feminist groups offered small contributions as an act of solidarity, recognising my decades-long work on women's health.

Support came from unexpected places, too. My hairdresser, who shaved my head when my hair began falling out during chemo, kept me in his prayers during *namaaz*. *"You'll recover soon, madam, Inshaallah,"* he messaged. His mother sent a *taweez* (amulet) for protection. Health workers I collaborate with in a rural area prayed at temples, and a colleague lit candles in a church. At a time when the world is increasingly polarised, these acts of compassion transcend boundaries that are often considered impassable.

Having spent years working with communities on public health, I experienced these interactions as collective acts of deep reciprocity, support, compassion, and healing. The solidarities I had tried to build across caste, class, geography, and religion returned to hold me, not as professional networks, but as human relationships. Such solidarity was a political and ethical form of care shaped by shared struggles and values. I came to understand more deeply that in moments of vulnerability, it is the strength of movements, and the care extended by friends and family, that sustain us. Our personal and political journeys are often inseparable, and it is at this intersection that hope is nurtured.

Peer solidarity

As treatment continued, I drew enormous strength from friends also navigating breast cancer who offered the most meaningful insights, despite my skilled and sympathetic oncologists and surgeons. Physicians, constrained by biomedical frameworks, often overlook the full range of what patients endure. Conversations with peers revealed how much of the illness remains unspoken, undocumented, and unacknowledged.

My friends shared their lived experiences—the sudden fatigue, the stress of losing hair, eyebrows and eyelashes, and the body's unpredictable reactions. They taught me to pace myself through the exhaustion and to remain alert to dizziness or disorientation. After a seizure, a fainting episode, and severe acral erythema, a painful skin reaction to chemotherapy—they insisted I record every symptom carefully to protect myself in a system not always attentive to nuance. Their encouragement was simple yet profound: *"One day at a time…keep telling yourself that everything will normalise." "Have healthy meals, rest well, and hydrate." "Try narthangai oorugai (dry lime pickle) when nothing tastes good."*

Every illness has a unique trajectory, yet peer solidarity offers a shared vocabulary, a way to reassure oneself, to locate courage, and to name what the medical system often cannot. It reminds you that you are not navigating this maze alone; somewhere, someone else is tracing a similar path, sending quiet strength your way. My peer network was a reluctant sisterhood, formed not by choice but by circumstance, and held together by vulnerability, resilience, and an intimate understanding of inhabiting a changed body. In this shared space, we became each other's companions, guides, and witnesses.

Ethics of care and shared agency

What moved me most was not only the help I received, but also the ethics underlying it. My friends and family did not take over my life; they expanded my agency while respecting my autonomy. Their care was relational rather than overbearing, grounded in attentiveness, reciprocity, and respect. These experiences reminded me of the ethics of care, which recognises interdependence not as a weakness but as an essential condition of being human. In the midst of illness, agency does not disappear; it shifts shape. It is exercised by accepting help, negotiating one's needs, and recognising that care is a shared practice sustained by relationships rather than individual endurance.

At the same time, this deeply affirming experience made me reflect on how many people may never have the opportunity to experience such solidarity and support. I was conscious throughout that my treatment journey was enabled by privileges of class, education, background in public health, and a circle of support. This very possibility of shared agency depends on conditions that are far from universal, raising important questions about what ethical care can and should look like in contexts where support is fractured or absent.

The costs of survival

Alongside the physical and emotional strain, my family bore the financial weight of treatment. Surgery, chemotherapy, radiation, and targeted therapies are costly; for example, a single dose of a HER2-positive targeted combination drug costs around Rs 2.6 lakh, and several doses are usually required. Many cancer medicines, especially targeted therapies, remain prohibitively expensive, leaving a large proportion of the population without access.

As I navigated this reality, I kept thinking of the Campaign for Affordable Trastuzumab in 2012–13, when many activists, patient groups, and public health practitioners pushed for compulsory licensing [1], so this essential medicine could be made available free in the public health system, and at an affordable price in the private sector. More than a decade later, that struggle for access to breast cancer drugs felt painfully, and personally, relevant again.

The burden of cancer care in India falls most heavily on low- and middle-income families. Treatment is only one part of the cost. Diagnostics, scans, medicines, hospital stays, travel, and the long-term loss of income—each adds another layer of pressure. Cancer insurance premiums remain so high that most families stay underinsured. Even Ayushman Bharat – Pradhan Mantri Jan Arogya Yojana, a government health assurance scheme or the Health Minister's Cancer Patient Fund does not cover the full costs. These systemic gaps force people to delay treatment, discontinue it midway, or take onerous loans.

Poor and low-income families depend on public hospitals, which lack essential infrastructure, staff, diagnostics, medicines, or palliative care. Delays between screening, diagnosis, and treatment allow the disease to progress, turning a treatable condition into a life-threatening one. Private hospitals may offer advanced care, but the costs are prohibitive for most. The result is a starkly divided system —inadequate and under resourced public healthcare on one side and advanced yet inaccessible private healthcare on the other, deepening long-standing inequities. Many of us have long argued that timely, affordable, and equitable cancer care should never hinge on class, caste, gender, geography, or insurance. It is a basic ethical and legal right—one we are still fighting to realise.

Another critical element of cost we rarely acknowledge is what families bear: the time and income lost while caregiving, the mental stress and the anxiety, often at the expense of their own well-being. These quiet burdens add up to a very real, often invisible cost that usually goes unaddressed.

Reconciliation, not confrontation

As my treatment progressed, I began to think more carefully about the language we often use around illness. I found myself resisting the familiar metaphors that dominate public narratives around the illness, which urge patients to "fight", as though survival depends on winning a battle through strength or courage. For me, cancer is a tumour, something that developed within my body, not an enemy attacking from outside. The language of battle, victory, and defeat treats illness like an invasion to be resisted, rather than negotiating a complex process unfolding within one's own body.

For me, this journey has never felt like a battle with an external enemy. I am learning to accept the changes in my body as part of my own physiology. I see it as a condition to understand, a disruption to navigate, and a biological event that calls for care rather than combat. I am not fighting cancer; I am reconciling with it to understand and navigate it with compassion, hope, and clarity. I remind myself that I am more than a diagnosis and that my life, though it has changed, still holds meaning, purpose, and hope. What sustains me is the understanding that living with illness does not require a retreat from the rest of my life.

Healing, I have come to realise, lies in presence and acceptance rather than in denial. Illness may isolate the individual body or parts of it, but healing is deeply collective — beginning within the self and extending outward into the communities that hold us. It is the care, solidarity, and connections offered by others that keep me grounded in a life beyond the disease.

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Reference

1. Campaign for Affordable Trastuzumab. Campaign Coordinator's letter to the Prime Minister, Manmohan Singh. 2012 Nov 5[cited 2026 Jan 20] Available from: https://donttradeourlivesaway.wordpress.com/wp-content/uploads/2013/01/letter-to-pm-on-herceptin_final.pdf