

# HEALING, REDEFINED: AN ANTHROPOLOGIST'S REFLECTIONS ON A MOTHER-DAUGHTER JOURNEY THROUGH ILLNESS

## 病非如此：一位人類學家的 母女共病絮語

*Just as her mother was diagnosed with Alzheimer's, the author, a professional anthropologist, received a positive cancer diagnosis. She applied her anthropologist's eye to their experiences, and the result is a touching and unsparing diary of daily life impacted by serious illness.*

When two life-shattering illnesses, cancer and Alzheimer's, strike the same family, what kind of upheaval will follow? Anthropologist and author Liu Shao-Hua had long been a researcher of the vicissitudes of human lives in interaction with their environment and circumstances. When she and her mother received simultaneous diagnoses, she began recording their experiences with an anthropological eye for detail, creating an intimate and objective record of a family coming to terms with grave illness.

As a cancer patient, she states that "to undergo treatment for cancer is to embrace the courage to survive". Her detailed portrait of the psychology of illness will help readers understand why facile encouragement can make those suffering from serious illness feel more isolated, or even abandoned. She also emphasizes the importance of vulnerability. Entrusting oneself to the care of others



Category: Memoir

Publisher: Locus

Date: 7/2023

Rights contact:

bft.fiction.nonfiction@moc.gov.tw

Pages: 280

Length: 97,032 characters

(approx. 63,000 words in English)

Rights sold: Simplified Chinese (Folio Beijing)

and engaging the support of family and friends can help provide what the afflicted need most: a sense of connection.

At the same time, her experience of cancer enhances her ability to empathize with her mother's condition. Even as her mother's memory declines, and her daily activities are curtailed, the author takes care to trace the course of her mother's thoughts, inferring her needs, and taking pleasure in her mother's quick retorts and easy smile. Even as losses are incurred, and the shroud of disease draws close around the family, many of the most cherished and truly important elements of life remain.

This unsentimental chronicle depicts every aspect of living with a grave illness, down to the burdens and worries borne by loved ones. At the same time, the course of these two diseases has the effect of deepening family ties, and enhancing the appreciation of life's precious moments. *Healing, Redefined* reminds readers that we start life dependent on our caretakers, and our life's journey is not complete until we return the favor. Aging, disease, and death are the darkness that marks the road of life, but with companionship and understanding, the journey will see many bright days as well.

## Liu Shao-Hua 劉紹華

Anthropologist Liu Shao-Hua earned her PhD at Columbia University, and currently works at the Academia Sinica Institute of Ethnology. Her research focuses on the interactions of society and global health issues from the perspective of infectious disease. *Passage to Manhood: Youth Migration, Heroin, and AIDS in Southwest China* (Stanford University, 2010) is one of her many research publications which have earned awards and recognition in Taiwan, China, Hong Kong, other international academic societies.

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By Liu Shao-Hua

Translated by Marianne Yeh

## Chapter 1: Crossing Boundaries

“Come on, follow my lead! One, two, three, four... Remember to breathe! Shouting it out helps you remember to breathe!” The energetic instructor led the group in aerobics, a class Mei enjoyed.

Mei was a veteran of this class at the fitness center, the longest-attending and oldest participant. She moved with agility and energy, keeping pace with the fast-changing rhythms. The instructor often praised her in front of everyone and sometimes recorded her on Mei's phone to share with her children and grandchildren, who would cheer her on.

But today, something was off. Midway through a Pony Jump right after the twist steps, Mei suddenly felt a bit dizzy. She tried again, but the unsteadiness persisted. Deciding it was best to play it safe, she switched to marching in place. As the instructor and classmates continued bouncing around her with enthusiasm, Mei felt out of sync, awkward, defeated, and threatened. The normally exhilarating movement of arms around her seemed disorienting, and the music she loved turned into an irritating noise. She quietly slipped away from the group, missing the instructor's wave. Lost in thoughts, she muttered, “I can't finish today's class,” as she headed towards the shower room, troubled by this unexpected turn.

A few days later, COVID cases were on the rise, and the fitness center was locked down again. Bored and restless from being home alone, Mei often forgot about the lockdown. She would head to the fitness center, only to be disappointed by the locked doors. Her family hired long-term care home service workers, but Mei continued venturing out. When the fitness center finally reopened two months later, Mei felt her stamina had waned and struggled to keep up with the routines she once breezed through. Despite this, she faithfully went to the fitness center every morning, only staying home when her children were home on the weekends.

Father's Day in 2020 fell on a Saturday, coinciding with the distribution of “stimulus vouchers” aimed at boosting the economy. Mei happily went shopping with her family at

Decathlon. Outings with her children and grandchildren were her favorite, as they always managed to make her smile.

The store was packed with people. While her grandchildren searched for sports gear, her daughter, Hua, helped her pick out some sportswear. When Mei saw the long line outside the fitting room, she grew impatient and told Hua that she didn't want to try on the clothes anymore. Hua then picked out a few pairs of socks that didn't need to be tried on. Unfortunately, the checkout line was even longer, adding to Mei's irritation.

The chaos and noise made the spacious store feel claustrophobic. Mei, visibly flustered, wore her discomfort on her face. Sensing her unease, the family decided to leave the store as quickly as possible.

Mei's son went to get the car while Hua held her mother's hand, waiting.

Suddenly, Mei frowned, on the verge of tears. She turned to Hua and said, "I really hate myself right now!"

Making a pounding gesture on her head, she continued, "My brain feels like it's blocked by something; everything is so fuzzy." Her voice was tearful. "I feel dizzy even when I walk. I'm afraid of falling."

Hua asked, "If you feel dizzy, can you still exercise at the fitness center?"

Mei replied with a hint of resignation, "I don't dare do anything too intense right now. I'm sticking to yoga – the slow kind."

Seeing Mei's worry and sadness, Hua was at a loss for words. She hugged her mother's slender shoulders and thought, "It must be terrifying to realize your brain isn't working right, and you have no idea how it happened, or what comes next."

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The changes hadn't come on like a thunderstorm but instead crept up on us like the moisture of a drawn-out rainy season, slowly seeping in and permeating through an old house. Though the discomfort had been brewing for a while, it wasn't until the paint began peeling off the walls that the symptoms became tangible and alarming.

In April 2017, after returning from a neighborhood-organized tour to Wu-ling Farm, Mother began experiencing excessive sleepiness. She slept from morning to night, skipping even her favorite eight o'clock soap opera. The sudden change raised alarms within our family. Three days later, my typically upright and healthy mother got up from bed but struggled to stand steadily, and her steps noticeably tilted to one side. Concerned, we rushed her to the emergency room, where doctors diagnosed her with delirium.

Delirium is an acute brain syndrome characterized by symptoms such as memory impairment, disorientation, incoherent speech, agitation, temporal and spatial disorientation, and visual or auditory hallucinations. In popular culture, it is often misunderstood as being "possessed" or mistaken for a mental illness outbreak, which can cause fear among others. These symptoms can resolve within hours to days with proper treatment. Delirium can be triggered by

various factors such as advanced age, illness, infections, medication interactions, and electrolyte imbalances. Dementia patients are a high-risk group for this condition.

The afternoon following her delirium episode, Mom awoke groggily, her eyes unfocused as she murmured, “Red threads. Three-quarters of an hour.” She extended her left hand, thumb touching the middle and little fingers. Thinking she was dreaming, I comforted her, and she drifted back to sleep. Minutes later, she woke up again, repeating the same words and gesture. This time, she asked, “Where are the red threads? Only half an hour is left now.” It no longer sounded like dream talk; the specific time reference made me take it seriously.

Mother spoke to me weakly but clearly, saying that Guanyin Bodhisattva had instructed her to wrap red silk threads around the middle and little fingers of her left hand within three-quarters of an hour to pass a test, or else she wouldn’t make it.

Upon hearing this, I didn’t care if it was true or whether I believed it; I immediately called my family. With no red silk threads at home, we split up to search for them, racing to deliver them to the hospital before Mother’s deadline.

Mother kept straining to keep her eyes open, anxiously pressing us for the thread. Her distress unsettled me. I hurried to the nursing station and requested red rubber bands, emphasizing, “They must be red.” The nurse found two for me without a word, leaving me to wonder, “Are they so used to all sorts of unusual requests here?”

I wrapped the rubber bands around Mother’s fingers, reassuring her that these were temporary until the red silk threads arrived soon. She nodded weakly and closed her eyes once more.

Time ticked away mercilessly. The half-hour window Mother mentioned was almost up when suddenly, her oldest grandson burst into the room, breathless. “Grandma, the red threads are here!” The athletic high schooler had sprinted to the hospital at champion speed, deciding the bus would be too slow.

Finally, the red silk threads were in place. Mother struggled to sit up, clasped her hands in prayer, murmured words of gratitude, and bowed repeatedly toward the foot of the bed, thanking the white-robed Guanyin she saw standing there. Finally content, she laid back down and drifted off to sleep.

The day Mother was hospitalized happened to be my elder brother’s birthday. Even though it was close to midnight, he insisted that he must blow out his candles and make a wish in Mom’s hospital room, hoping for her recovery. Mother was sleeping peacefully, clutching the red silk threads in her hands, so the family instead moved to the adjoining lounge to light the candles and cut the cake. My brother took a slice to place by Mother’s bedside but suddenly rushed out of the room, urgently whispering to us, “Quick, come see Mom!” We abandoned the cake and hurried into Mother’s room. Everybody was stunned to see her practicing yoga on the bed, stretching into splits. She greeted us with her usual laughter and jokes, seemingly unaware of why she was in the hospital in the first place.

Just like that, Mother dramatically recovered.

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After Mother's delirium episode, our family recognized that she was declining and anticipated more challenges ahead. Yet, when faced with each instance of something amiss, distinguishing between normal aging and signs of dementia wasn't always clear. Amidst our hectic lives, we struggled to grasp Mother's new reality but had yet to fully calibrate how we perceived and treated her. Life was already stressful, and although Mother was deeply affected by the internal storm of change, it wasn't always apparent from her outward appearance. She, too, strove to uphold her familiar lifestyle and appearance. We all yearned for life to remain unchanged.

The reality, however, was that life was constantly evolving, and our daily routines would soon reflect this reality.

Over the next year or so, as Mother faced increasing difficulties, our family finally confronted the possibility that she might have dementia and took her to see a neurologist. Thankfully, Mother also sensed something was wrong and didn't resist seeking medical help. It was a relief, considering how many elderly individuals often refuse hospital visits when ill. Mom's cooperation likely stemmed from her familiarity with frequent specialist visits with us; she may not have realized which department she was visiting this time.

In July 2018, after extensive testing, Mom received a diagnosis: the early stages of Alzheimer's Disease. Finally, our family had a medical explanation for her myriad challenges. It turned out that her puzzling behaviors were all manifestations of dementia: her cooking became excessively salty from repeated additions of salt; she would start looking for rice just after she had placed freshly washed rice in the pot; she frequently stocked the fridge to bursting, leading to spoiled food; when fetching water for her medication, she would forget her task upon reaching the dispenser; she would take a double dose of medication upon seeing yesterday's forgotten pills in the pillbox; afraid of being nagged about forgetting to take her medicine, she would hide the pills in plastic bags inside her closet; she often complained about friends or relatives saying upsetting things, becoming easily angered; she accused people of stealing from her room, constantly searching for misplaced items; to prevent further "thefts," she would hide items meticulously, only for us to later find food, cash, scissors, jewelry, cups, bowls, and even piles of tissues in various boxes, cabinets, drawers, walls, bathrooms, and kitchen corners. The house was a labyrinth of forgotten items hidden by Mom, their types and locations often baffling.

Yet, Mother's hiding spots were always within what she considered her personal domain: her bedroom suite and the kitchen. This revealed that despite her cognitive decline and confusion, there was still a certain logic to her actions. It gave our family a starting point as we tried to decipher the reasons behind each behavior and the subjective reality of time and space she experienced at the moment.

Despite being diagnosed with a disease, Mother remained physically robust. She continued her daily trips to the fitness center, bought groceries, and cooked for the family. It was as if she refused to acknowledge her illness, instead insisting on living her life as usual. Despite

her mental decline, her physical strength and mobility remained strong. We couldn't control her; we could only support her independence.

Ultimately, life had to continue. For an elder who had accumulated a lifetime of nuanced relationships and worldly wisdom, it was paramount to maintain dignity, freedom, and her role in caring for the family.

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Mother was aware of her mental decline but still tried to live independently. Worried about the challenges of my upcoming chemotherapy, she even offered to move in with me so she could take care of me.

After my surgery, Mother went out of her way to buy a chicken to make me nourishing chicken soup. She loved visiting various markets to find the best ingredients. Whether it was the fruit and vegetable market in Taipei, the traditional market in Yung-ho, or the evening market near our house, she always had her preferred vendors and unique quirks. Watching her return with bags full of meat and vegetables in the sweltering summer heat, then bustling around the kitchen, I quietly muttered an apology: "Mom, I'm so sorry to still make you worry at my age."

Mother didn't look at me as she continued preparing the vegetables. After a long silence, she spoke with her head bowed, her voice trembling as if she was trying to control her emotions: "I'm so happy to have you as my daughter. You've always been caring and helpful, even when you were little. You've always been a good student and never gave me any trouble." After a brief pause, she added, "And you know how to make money, too."

I never expected my already ailing mother to share such heartfelt words with me. Her words brought me comfort and even a sense of joy. It turns out that "being able to make money" was something she saw as one of my strengths. I had never thought of it that way before. As I sipped her chicken soup, I felt both physically and emotionally healed.

When Mother came out of the kitchen, she added one more thing that brought tears to my eyes: "If Mommy can do it, you can too."

Thirty-two years ago, when Mother was fifty, she was diagnosed with breast cancer and underwent a full course of chemotherapy. Back then, Taiwan didn't have universal health insurance, and the standard practice for chemotherapy was direct injection, which damaged the blood vessels where the drugs were administered. Even after recovering from cancer, patients might experience aftereffects, such as the loss of elasticity in the blood vessels of one arm, making it impossible to measure blood pressure in that arm. There were also few methods to mitigate the discomfort of chemotherapy, making the side effects even more severe. Nowadays, with universal health insurance, it's common to perform a minor surgery to insert an artificial blood vessel before starting chemotherapy. The artificial blood vessel is removed after treatment to protect the patient's blood vessels from damage. In other words, successfully recovering from cancer back then was much more challenging than it is with more advanced medical treatments we have today. But Mother had persevered and came out stronger.

By some twist of fate, I was also diagnosed with cancer at fifty. With just a simple sentence, Mother used her own experience to encourage me. Even though she was sick herself, she was still trying to lead her little chick forward like a mother hen.

Before Mother's Alzheimer's diagnosis, I once pestered her to cook a dish I used to love. She suddenly looked embarrassed and said something that left a deep impression on me: "The mom you know now is not the same mom as before." Was she asking for my understanding, or was she struggling to recognize the unfamiliar person she had become and saying goodbye to her former self?

Mother was well aware of her own changes; but when I got sick, she still tried to help me.

During my treatment, there was a time when I didn't have enough help. Chemotherapy weakened my immune system, making it too risky for me to live with my large family due to the potential for infection. Finding someone to cook for me was difficult, which worried Mother. I had always been afraid to handle raw meat and once spent seven years as a vegetarian because of this. Although I now ate meat, I only knew how to cook vegetarian dishes. However, chemotherapy patients need a lot of high-quality protein. Mother asked my brother to bring her to see me and insisted on staying to take care of me. Seeing her so anxious made me want to cry.

In my adulthood, Mother's cooking became our most intuitive connection. Whenever I was away for school or work, I would always call ahead to request my favorite dishes, and Mother would use food to call me back home. Once, I had an argument with her and, in a fit of sulking, stubbornly refused to go home. Two months later, my family sent me a simple message from Mother: "I'm going to make oyster vermicelli tonight." It felt like receiving a secret password and, feeling sheepish, but relieved, I went home.

In my illness, I longed for Mother's care. But she wasn't familiar with where I was staying to recover. How could I let my mother, newly diagnosed with dementia, move in with me to take care of me? The unfamiliar surroundings would only worsen her condition. Looking at Mother sitting in front of me, her frame even smaller than mine, and hearing her repeatedly express her desire to stay and take care of me, I firmly shook my head and assured her that I could manage on my own. Despite my assurances, Mother was insistent and almost begged to stay.

At that moment, I understood the true meaning of "Mother's Strength". Despite her own fragility, Mother was solely focused on caring for her ailing child. However, given her advanced age, the time she had left to fulfill her wish of helping me through my illness was limited.

The course of my illness was very different from Mother's. For me, the journey had two main phases: six months of treatment, during which I was extremely fragile both physically and mentally, followed by a period of rehabilitation where I felt rejuvenated and full of life, almost like a new person looking forward to recovery. For Mother, however, the expectation was a gradual decline, with the best hope being that her condition would not deteriorate too rapidly.

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When I looked back carefully, I realized that, over the years, Mother had been intermittently telling us about changes in her life, among which many were actually dementia symptoms. Sometimes our family recognized it; other times we didn't.

At the onset of her illness, Mother's denial wasn't necessarily due to a lack of awareness. She likely didn't want to expend her energy trying to grasp the doctor's instructions and her family's reminders while grappling with her own confusion and frustration. Moreover, she resisted the idea of transitioning from a fully independent adult to a child who needed constant guidance and care.

In reality, Mother had long been aware of the extent and specifics of her changes. However, like many patients who might intentionally ignore their symptoms before a diagnosis – whether for self-comfort or to secretly wish them away – she kept most of her confusion and fear to herself. She tried to conceal these feelings, yearning to continue living independently, exercising, shopping, delighting her family with her cooking, and enjoying life's pleasures. Her inner vitality remained strong, and she wanted to stand firm, hoping for a better tomorrow.

Despite this, while her self-image remained vibrant in her mind, it was crumbling in front of our family.

After Mother's diagnosis, we endured two tumultuous years marked by uncertainty and near chaos. During this time, Mother experienced increasingly frequent incidents, losing her keys, wallet, hats, clothes, and umbrellas, and often accusing others of stealing from her. We constantly worried about her getting lost and tried every method imaginable to prevent it – bracelets, necklaces, tracking devices, phone apps – but nothing worked. Mother, sharp and cunning, found ways to thwart our efforts, stubbornly refusing to give in.

Throughout this period, Mother's condition was like an unpredictable time bomb, ready to go off without warning. It consistently elevated our blood pressure, causing frustration and anger. Our once peaceful and harmonious home could transform into a pressure cooker in an instant.