



A PENGUIN READERS GUIDE TO

THE TINCTURE
OF TIME

Elizabeth L. Silver

Q&A WITH ELIZABETH L. SILVER

Why did you decide to write this book?

Initially, I began writing down everything that happened in order to best present my daughter's story to doctors, so that they could help her, as she couldn't speak for herself. Months later, writing turned into a form of coping, a means of expression by which I could make meaning of what was happening. By placing my thoughts on paper, I was able to understand them, and in turn live consciously through my daughter's recovery and my early months of motherhood. As she recovered, though, I became fascinated by the concept of uncertainty—not knowing what a prognosis would be, why we get sick, why injuries occur—and realized that although this story is all-consuming to me, it, like any individual story, is small. What is enormous, though, is the unknown world of medicine that we avoid. By surrounding myself with literature and philosophy and other case studies with similar subject matter, I was better equipped to understand what I was facing.

I'd love for people to take away a plan with which they can attack their own uncertain medical situations. We can intellectualize our traumatic experiences, combining the emotional with the practical. Medical crises can be very lonely and disorienting, and I hope that this book can serve as a companion and a guide during these emotional times. I hope it will provide community and support, and help others realize that they are not alone when experiencing something similar. That is what books have always done for me.

How is Abby doing now?

She's four years old now and brilliantly thriving in every category. She's also a loving big sister. As people frequently say to us, "If you didn't know, you wouldn't know."

The book is divided into three parts: Acute Uncertainty, Sub-acute Uncertainty, and Chronic Uncertainty. Can you talk about this format?

Acute, Sub-acute, and Chronic are the three stages of disease used by physicians around the world with respect to managing and treating illness and injury. Shortly after I began writing about uncertainty, I realized that this terminology can also be applied to the subject matter, no matter the severity and no matter the type of illness—be it as large as degenerative neurological disease, cancer diagnosis, or brain injury, or as small as a routine tonsillectomy, appendectomy, or even the flu. Uncertainty is so nebulous, so difficult to comprehend, that having even a loose semblance of a structured approach was helpful to me. As a result, writing the book within that paradigm made perfect sense for my own story and also for the stories of those I interviewed and researched.

What was the experience of writing this book? Thinking back on it now, are you surprised by anything that came up in the process?

Writing this book was at once painful and cathartic, a masochistic need to relive some of the most unpleasant moments from my life in order to accept them. But by pulling back the curtain on the general concept of uncertainty in medicine, I was able to extend this book beyond my story to those of countless others, which helped me understand what I was exploring in my writing and experiencing in my life.

I interviewed dozens of experts and individuals experiencing medical uncertainty, and though only a handful of their stories made it into the book, our discussions will stay with me forever. Many faced long-term, ongoing

uncertainty, which invariably turned their chronic uncertainty into the only known variable, while others shifted my perspective on what uncertainty is, what a medical crisis is, and helped me understand where I fell in the spectrum.

Initially, I was intrigued by the concept of “uncertainty in medicine.” What does that mean? Though it can be partially understood as the unknown, it is not so entirely. For example, many people shared their medical crises or bizarre medical histories with me, which, while fascinating, did not necessarily fall into the category of *uncertainty* in medicine. It fell into the “strange and unusual” medical category, or the “frustration with medicine and doctors” category. Other people focused on decision-making trees, and the question of how to approach a medical decision when faced with several options. Though this also shares some traits with uncertainty, this is ultimately about decision making when you actually have options. I was very interested in situations where that wasn’t even the case.

While conducting interviews, I also realized that uncertainty in medicine is, in many ways, a litmus test for how people view the world. I ended each interview with a fast association test for their gut reaction to the phrase “medical uncertainty.” The most frequent response was “fear,” with “powerlessness” and “frustration” a close second—all words sharing a particular connotation. Sure, there were a handful of responses in the positive realm, such as “challenge” and “discovery,” but broadly speaking, it was a concept that left people needing something: something comforting, something healing, something . . . more.

Speaking with many experts and individuals who had gone through something similar, different, less traumatic, more traumatic, helped me place my own experience in a greater context, and also helped me realize that this book, while about my own story with medicine and my daughter’s traumatic medical crisis, is also a book about how our approach to our health is a metaphor for how we approach life.

“The Bake Sale” is a beautiful section of the book that brings to life the “mystical belief that when at least forty women bake challah, the traditional Jewish bread for Shabbat, with specific prayers for recovery for one person, there is a segulah, or a good omen that God will hear them and help.” Can you speak to this experience and the role that religion played for you during Abby’s first year?

Thank you. Religion has always been an important element of my identity, my culture, community, and broad view of the world, but it hasn’t necessarily been a guiding force in times of need. This isn’t because it hasn’t been there for me, but rather because I’ve never sought it out during those moments. I never made “deals with God if only,” and don’t think specifically about prayer in the traditional sense. Though I am a strong cultural Jew, I am not an Orthodox (or extremely religious) one.

One of the most fascinating elements of religion for me has always been its ambiguity played out as vehement and infallible certainty for so many people. But in many ways, religion is in fact the essence of *uncertainty*. It is *faith*, the opposite of certitude and conclusiveness. We refer to faith and religion as a leap, a question, a belief in something intangible. And yet in times of great uncertainty (war, illness, personal and political crises), many people turn to the most uncertain of sources: religion. In many ways religion—be it, for example, Christianity, Islam, Hinduism, or even my own experience with Judaism—offers an unknowable answer to an unknowable question. Nevertheless, religion is embraced because it is one way that people can find a rope when drowning in an uncertain moment. There is no one person who can prove that religion doesn’t offer the answers, and that is in itself a form of certainty for many people.

“The Bake Sale” was an unexpected and beautiful moment in my life with Abby. Other people may rely on prayers with specific requests to a God, whoever or whatever that is to them, but for me it was a moment of community, a moment of abstract spirituality, a moment of love.

When you were experiencing long periods of uncertainty, what helped you get through this time?

Writing this book, quite simply, helped me get through extended periods of uncertainty. Channeling my fears, my projected forecasts, my unknown future not only into prose, but also into research, interviews, and literature helped me find a place to collect my thoughts and also forced me to make meaning of them. By speaking with others, I felt community, I felt understood. By reading, I felt connected. By writing, I felt heard. And depending on the stage of uncertainty I was experiencing, I relied on different factors.

On a very concrete level, Abby's doctors—specifically her incredible pediatrician—and her exceptional physical and occupational therapists helped me a great deal, as they were constancies in our lives (and home) four times a week. Creating a semblance of normalcy with them and with my family and friends may have been the ultimate aid in getting through extended periods of uncertainty, most specifically the sub-acute period.

Talk a bit about your personal relationship to professional medicine. How did your upbringing impact how you viewed Abby's condition initially?

I have been lucky to live near doctors for much of my life: first with my father, who is a general surgeon, and then with my sister during her internal medicine residency in New York, and now with my husband, who is a rheumatologist. Of course, this doesn't shield me from illness or injury, but it has provided me with an intimacy with medicine so much so that I am not afraid of hospitals or doctors, nor am I necessarily in awe of them. They are people, plain and simple, and this very privileged relationship has helped me develop a vocabulary with which to communicate with them. I also worked briefly as a medical malpractice defense attorney, which essentially unraveled all that comfort and intimacy with medicine in one short year. It was my job to focus one hundred percent of my day on the one percent of things that go wrong in medicine, and these juxtaposed identities that often worked against one

another when my daughter was ill.

Nevertheless, my daughter's injury exists independent of this identity. Doctors' kids get sick and injured just as much as those without the privilege of medical intimacy. I am not a doctor. I am not a nurse. I am not particularly good at math, and though I'm fascinated by science, it wasn't the first subject I chose in college and graduate school. As a result, I hope that this book, in many ways, is sort of a conduit between the medical and lay worlds.

What does the title, The Tincture of Time, mean to you?

"The tincture of time" is a mantra for anything that poses the proverbial question "what if?" It is the poetic version of the medical "watchful waiting" advice that hasn't changed in centuries. It is a literal prescription that doctors provide for patients when there is nothing else. I learned of the phrase while waiting for Abby's first MRI results. My husband and I were waiting nervously, discussing the wide range of outcomes for such a profound injury. He told me that we couldn't predict what would happen or necessarily know when we'd have a prognosis. He said that this was just *the tincture of time*, a phrase he sometimes writes at the bottom of his own medical notes when there is nothing to do but wait for an answer. It's not the cliché that time will heal all wounds, because it may for some and may not for others, but rather the prescription of time as the only source of answers. It is now a phrase I will rely on for the rest of my life whenever something creeps into it without a map. It is a symbol of life.

QUESTIONS FOR DISCUSSION

1. What does the word “uncertainty” mean to you? What about uncertainty in a specifically medical context?
2. The book is divided into three parts: Acute, Sub-acute, and Chronic Uncertainty. How does this structure inform the narrative?
3. Memory—in particular, its mutability—is a theme that runs consistently through the book. Can you think of an event or period that you and a loved one have remembered entirely differently? What is your way of keeping the memory of particular events or people alive?
4. What was your reaction to the scenes in which a social worker asks Elizabeth and her husband a series of sensitive questions about their care of Abby (pp. 49-52)? If you were the social worker, how might you have gone about getting answers to these questions? If you were the parent, how might you have reacted?
5. How does feminism play into the narrative? Does gender make a difference in medical situations or situations of trauma in general?
6. Elizabeth writes at length about her feelings of guilt with respect to Abby’s injury. How much does guilt play into our decisions as parents in and out of medical contexts?
7. What do you make of the role that religion plays in this narrative, particularly the scene of the Jewish “bake sale” (pp. 107–114)?
8. Writing about Abby’s trauma and treatment was an important coping mechanism for Elizabeth. What are the different strategies you use to cope with challenging or painful situations?

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9. How much do you rely on statistics in medical contexts? Do you find that they hurt or help?
 10. Elizabeth is conflicted about the idea of describing Abby as a “survivor.” What does that word mean to you, and how might it affect one’s sense of self?

“GESTATION”

This original essay is reprinted with the permission of Lenny Letter.

My grandmother died one month before I gave birth to my first child. She was 93 years old and passed away surrounded by her family at home in Los Angeles. My husband, Amir, and I named our daughter, in part, after her. This act, naming a baby after a lost loved one, is meant to reflect a more profound version of trite ‘cycle of life’ platitudes nobody really wants to hear at funerals. The dead are still with us; our lives go on. It’s a nominal reincarnation of sorts.

Two years later, I was pregnant again with my second child—this time, a boy. We shared the news with our family, and there was a week or two of conventional grandparent joy, the anxious anticipation of a growing family, and a heavy focus on the life to come. My parents were thrilled, as were Amir’s—particularly his father.

When I was three months pregnant, we learned his father’s diagnosis: Acute Myeloid Leukemia (AML), or the disease that would eventually turn into AML, one of the deadliest cancers. Amir, a physician, immediately understood the gravity of his father’s condition. You cannot remove a tumor from a bloodstream. You cannot cut it out. You cannot necessarily radiate it away.

When I was four months into my pregnancy, I shared the news with select friends. This wasn’t exactly a time to celebrate. I told friends I was pregnant in the same sentence I told them my father-in-law had cancer. Linguistic attachments, two halves of my life connected.

At five months, I underwent an ultrasound to make sure the baby was healthy. They found something troubling in his heart. I was feeling ill, breathless. I had stopped exercising because every time I moved, I felt contractions. My first pregnancy had drastically changed my perspective on gestation. My daughter, though born healthy, suffered a stroke at six weeks and spent significant time in the NICCU. I couldn’t have a second sick baby. One time, shame on fate. Two times, shame on you.

I called my mother-in-law from the hospital. I knew that she was in another wing of the same hospital at the same time with my father-in-law while he underwent chemotherapy.

“Do you want to take a peek at your grandson?” I asked her, hoping this might bring her joy, even if it was only momentary. After all, we almost never spoke of my growing belly. The topic, though visible to all, was toxic, as if discussing one discounted the other.

“Yes,” she said. I heard the excitement in her voice. “I’m just sitting here.”
“Will he be okay if you leave?”

“Yes,” she said, and she walked several blocks to be by my side to watch a new life developing on a screen.

Within moments, the doctors told me that there was likely nothing to worry about. My son’s heart seemed fine, but we should repeat the ultrasound again in a month.

Likely nothing.

Nothing to *really* worry about.

Words of poor comfort to a family whose emotions were split open.

At the six-month mark of my pregnancy, my father-in-law was getting sicker. He didn’t want visitors anymore. His immune system was gone, and he was living in a bubble at his home. We didn’t know how much time he had left but still held onto the desperate hope for a bone marrow transplant, which offered him a slight chance at remission.

At seven months pregnant, we dropped by Amir’s parents’ house unannounced on a random Sunday afternoon. Everyone was in a particularly good mood. My father-in-law was laughing, my mother-in-law smiling with him, my sister-in-law and nephew making jokes. A house filled with life and laughter, frozen in a Sunday afternoon of nothingness.

But my father-in-law had just been disqualified from the bone marrow transplant because he was too sick to survive the procedure. So with few options remaining, the bubble was disassembled. The gloves and masks were

gone; there was no longer a need to keep the home sterile to make sure he would last until the transplant. The lack of human contact that had pervaded his existence for seven months was forgotten, and Amir walked over to his father and touched his skin for the first time since his diagnosis. I watched from afar as they embraced by the window, two figures still until their bodies rippled into one.

On the drive home, I took Amir's hand in mine. The baby was moving, his hand gliding under the skin of my belly. I didn't place Amir's hand on it.

I was away from Amir and his family when it happened, but felt my belly rumble around his time of death.

At the funeral, Amir spoke intimately of his father, detailing their life together, mourning the life he'd hoped they would have as adults. He spoke of the emptiness in his daily routine, the kindness he learned, the generosity of spirit. The fact that his father would never meet his own son. My belly thundered, and I swallowed a mouthful of vomit. I loved and missed him, too.

When I'd met my future in-laws over ten years earlier, Amir's father had struck me as different. A traditional "meet the parents" dinner ended with an oversized hug and an "I love you." Amir told me it was *just because*.

"Well, I love you," Amir said to me, "so that is enough for him."

"He loves me just because *you* love me?" I asked. "That doesn't make sense. Doesn't he want to get to know me first? See my life's resume? Meet my parents?"

"Nope," Amir nodded, placing his arm around me. "Seeing this is enough for him."

For seven days of shiva, we told stories and laughed and cried, and I listened to questions about the baby's name. Strangers, distant family members, colleagues all came up to me, saying, "It's the cycle of life."

People I didn't know touched my belly, smiling mournfully.

“It’s going to be such a help to everyone.”

“How wonderful that you’re having a baby. And a boy, no less.”

“Yes,” I would say, rubbing my belly, and then I would walk away, shielding my eyes, wanting to scream, no.

His face couldn’t be photoshopped over another to complete the family photo. He would be a boy on his own. And it was up to me alone to ensure that his growth was healthy, that his development continued on track. This baby was going to be born no matter the timing, no matter the need, no matter the hole he filled, whether it was the following day, the following month, or anytime thereafter.

But as we buried my father-in-law, people I didn’t know continued to approach me, always touching my belly and informing me of my unborn child’s role in this cycle of life.

“You’re going to name the baby after him, right?”

“This is going to be the best thing to happen to everyone.”

But there is no “best thing” that happens at a funeral.

Hours later, with the baby moving visibly through my dress, Amir and I walked into a bedroom at his mother’s house and, away from the guests, came up with our son’s name.

By the time I was eight months pregnant, I had been sent to the hospital for preterm labor multiple times. I spent many evenings strapped to a pink and blue monitoring belt to ensure that the baby was still healthy. He had irregular heartbeats. I was contracting too early, too quickly, too evenly. I was over thirty-five with a medical history. Nobody was willing to take a risk, so at any glimmer of an irregular fetal heartbeat, I was whisked away to Labor & Delivery for a day-long stay of tests and ultrasounds and cervical examinations, just a few floors above the bed where my father-in-law last slept.

Amir wasn’t with me for most of those visits. I navigated these appointments alone, spent many evenings admitted into the hospital alone.

Shopped for baby clothes alone. Rearranged our apartment alone. While we were mourning the loss of his father separately, he was split, wanting to feel excitement, but furious with himself for feeling any.

He rarely spoke of my pregnancy—of the excitement to come, the fear of raising two children, the novelty of a boy, my emotions and body's changes, the internal struggles of pregnancy, which I swallowed until they led me to the hospital five additional times in one month. We didn't fight; we didn't talk much at all. And it wasn't his fault. Nor was it mine. But if I focused too much on sadness, the heart rate that was in trouble would worsen, and so I was forced to look one way while Amir looked another.

At nine months, my pregnancy became a topic of conversation.

"You know, he was so sad about the baby," my mother-in-law told me about my father-in-law. "He was wondering if you were going to name the baby after him."

She paused for a moment, unsure of my reaction.

"He *wanted* you to."

In truth, he hadn't spoken of the baby much to me or Amir. He hadn't been able to accept that he wouldn't be there for his grandson's life. What all of us didn't realize is that he wouldn't be there for his grandson's birth.

A few weeks later, I gave birth to a healthy boy. His name was given at his bris in the same home that had hosted the same guests a little over sixty days earlier for the Shiva. Children played in the backyard, their voices cackling through the windows, just as they had two months earlier. A different rabbi spoke about the entryway to life instead of its exit. My mother and mother-in-law stood together as my father held the baby during the ceremony. I spoke about the name we passed on from Amir's father while he helped with the circumcision.

And time stopped, only to be sped up again over the next six months with the renaissance of responsibility, dual childcare, careers, life, dishes and laundry and diapers. But in that brief moment when the ocean of time seemed navigable, Amir and I held each other, our son, and our daughter, and for the first time in nine months, were reunited.