

Lesley Stern

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### Diary of a Detour

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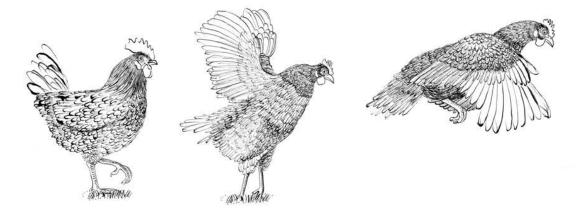
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Lesley Stern

With illustrations by Amy Adler



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COVER ART: Chickens for Lesley @ Amy Adler 2019.

Courtesy of the artist.







IN MEMORY OF THOSE, dear to me, who died during the writing of this book. With some I traveled fleetingly, others have shared many journeys and detours, all have made my life, and Diary, richer.

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Elvis, the King of the Cats

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#### **SEPTEMBER 28, 2011**

Chickens changed my life. Saved my life. Though it is also true to say that as we ride the stormy waves of birth, old age, sickness, and death, many things, people, and events change what we call *life*. A life is merely a conglomeration, a concatenation of effects and affects, often unpredictable, though even when predicted, things seldom turn out as expected.

And it was not by chickens alone that I have been saved. But among all the therapies—chemo, meditation, acupuncture, Feldenkrais, naturopathic treatments, exercise—chickens, four glorious chicklets-becoming-hens, have changed things most dramatically. Holly, Lula Mae, Sabrina, and Funny Face flap, flutter, and jump onto anything that might resemble a perch, including human shoulders and heads. They frequently land together on one side of their feeder and tip it over. They also landed like a miracle, about six weeks ago, on me, and tipped the balance from death to life.

I have an incurable cancer, a form of leukemia called CLL (chronic lymphocytic leukemia), so like everyone else I am going to die but probably not tomorrow. Still, life was becoming rather hard to live. Now, after spending the summer in chemo-and-chicken therapy, I have been given a reprieve. I have been wanting chickens for years, and for years have been putting it off, there were always other things to do, work to get done, fetish desires to satisfy. CLL is one of the slow cancers. For some people it does not progress beyond what used to be called the indolent stage, for others it can race along alarmingly fast for a slow cancer. My symptoms just got gradually worse, though I wanted to defer treatment for as long as possible since once you start treatment you also start damaging your body's ability to fight back.

As my oncologist, Dr. K, says, there are no such things as side effects. All drugs have a range of effects, some good, some not so good (and sometimes the connection between good and not so good is knotted, complicated, measurable only over time). So when he said, I think it's time to start treatment and I saw the summer disappearing into an infusion center, the absolute ghastliness of my condition (so far no treatments have lengthened life for CLL patients) took hold, gloom defeated a habitual Pollyanna-ish reflex. And then, in the midst of gloom, my thoughts turned to chickens. Chickens turned into obsession.

Soon I could think of nothing but breeds of chickens and what color eggs they lay and coops and ventilation and chicken manure and compost and predators and fencing and automatic watering and mites and fleas and worms and herbal remedies, and the chirruping noise that chicks make. I dreamed of collecting fresh eggs from free-ranging chickens fed on weeds and greens and fruit from the garden. I could smell the omelets made from these eggs, buttery and sizzling, sprinkled with herbs. I could also smell the chicken shit and rapturously and endlessly imagined the compost we would have, how contentedly my garden would grow. J, my partner, embraced the idea even more wholeheartedly than I, encouraging a flagrant defiance of budget in order to get the project happening. I spent endless hours on the internet, ordering books from the library, reading back copies of Backyard Poultry, visiting friends and perfect strangers with hens in their yard. Planning in minute and exacting detail. My treatment lasted three months, and some of that time was spent backbreakingly (not me) and obsessively (me) assembling el palacio de las princesas, so named by my friend Isabel. And then the ordering. And then the arrival one morning, through the mail, of a cardboard box containing four day-old chicks. Through all this demented focusing on chickens I had been feeling not too bad, forgetting the "C" word. And now my forgetfulness morphed into full-blown happiness. We started laughing. The tiny chicks are fluffy and adorable but also absurd in their pomposity. As the chicks grow their absurdity expands, keeping us laughing, tickling a severely compromised immune system, kicking it into gear.

Two weeks ago I saw Dr. K, and he told me what I already knew, could feel, that so far the results are good. This isn't the end of the story; there will be more tests and more treatment sooner or later. But for the moment I'm feeling better than in years and it feels extraordinary, though I guess it's actually normality that I'm feeling.

This book was sprung into being by the chickens, and it will follow, through many detours, the ways that a vague idea becomes focused as a consuming passion. It's also about other things: just as a life can be changed by a chromosome going awry, so it can be transformed by a chicken, or a book that one is reading, or a feral plant that takes root in your garden and slowly grows into an intriguing presence, altering the culture of the garden and making you see and feel differently.

2 CHAPTER 1

The Time It Takes
(By Way of an Introduction)

If I write in order to fend off the feelings of isolation and uncertainty that chronic illness can foster, I write for other reasons too, some merely neurotic, some to do with the pleasure afforded by any addiction, and for some reasons (though *reason* seems far too grand a concept) to do with a sense that putting into words this thing called illness produces a materiality, albeit chimeric and diaphanous, something that can spark recognition, something that can be passed from hand to hand, blown through the air or kicked from one place to another.

Diaries are generally chronological, moving forward in a relatively straight line. This one deviates from the straight and narrow, and is not really a diary, more like a series of meditations, stories, excursions, escapes, tirades, and pirouettes. Nevertheless, it shares some features with the genre of the diary. It began as a blog, written sporadically to inform friends of how treatment was going, asking for a ride to the hospital or setting up a rota for meals. Gradually, as my health improved, some of these entries began to take shape as small essays, or ruminations, they became detached from the blog and morphed into a book. This involved a shifting of the "I," a transition from very personalized and banal reportage to the emergence on stage of a more dramatized, a more fictional "I."

While *Detour* does not, then, follow the path of a disease, step by step, nevertheless a bit of a chronology might be useful, a map, a background against which to read the excursions and meddling with time. I was diagnosed with CLL in 2008. A new primary care physician, MM, asked me about fatigue. Yes, I said, but there are probably reasons for that. Work. Let's do some blood tests, she said. In fact she knew, as she later told me, what to expect because, when she became my doctor she looked over my record and saw that since 2004 my white blood count had been high. This was before you could see your test results online and you (or I) took

the doctor's word that everything was fine. I saw a hematologist who referred me to Dr. K, a leading researcher in CLL and very fortunately for me located at the university where I worked in San Diego. Three years later I began my first chemotherapy, a combination of high-dose prednisone, a steroid that slows or stops the immune system processes that trigger inflammation, and Rituximab (both taken as infusions). Rituximab is not actually a chemotherapy, it is an immunotherapy, but generally the treatments are referred to here, and more generally (at the hospital, for instance, by the insurance companies), as chemo. Two years after that, in 2013, I had my second treatment (as part of a trial)—a combination of Rituximab (taken as an infusion) and Revlimid (taken orally, as a pill). Revlimid, an immunomodulatory agent, was seen as a twofer: it was hoped that, in addition to acting on the CLL, it would also promote immunity. There was no expectation that any of these treatments would produce a cure. There was hope, though, that they might provide temporary relief from the symptoms and partial remission.

This book begins with the first treatment in 2011, since at that point something other than medicine entered significantly into the treatment. Call it chickens, or call it obsession, or call it a detouring away from the medicalization of cancer, a deflection from immersion in the idea of illness. The book takes off, however, two years later with my second chemo treatment in 2013. It ends in 2018, ten years after diagnosis (and after fourteen years of living chronically with CLL).

In this account it is illness that determines the march of time, but the chronology is not entirely indicative of the way the book unfolds. People often speak of a cancer journey or, more specifically and in my case, of the CLL journey. Although I recognize that analogy, I bridle against the habit illness has of commandeering attention, and even while this book aims to put into words the experiential dimension of CLL, that very project entails a shadow boxing with the phantoms of illness, a deploying of tricks to nudge the self-importance of cancer, now and then, into the background. There are other backgrounds that sometimes leap forward into sharp relief and speak to obsessives of various stripes—gardeners, for instance, food aficionados, fermentation freaks, travelers and fellow travelers, cat lovers, bookworms, straying Buddhists, and pedantic amateur scientists. Not that it is always a matter of trickery. Once you start writing, the writing escapes your grasp; like an octopus it slithers out of its cage and spreads tentacles in diverse and unexpected directions.

If there is a tension that animates the book, between time as a chronology, where events are narrated sequentially, and time as a time-out, where sensations and feelings expand the experience of the moment, the minute, the hour, there is also a tension between language that evokes and lives in details of the everyday and the language of science. These different registers can be read as speaking to

4 CHAPTER 2

one another, as a blurring of the categories of science and affect or emotion. Or the pieces that privilege one mode or the other can be read entirely separately (though they do have a habit of interrupting each other), you can jump around, skip chunks, circle back.

One way I found of fighting off the imperiousness of the malady was paradoxically to enter further into the lairs of medicine, to try to develop at least a rudimentary grasp of the science of CLL or, more generally, of cancer. Science is mysterious to me, slippery and evasive. So grappling with this, putting it into words, was an invigorating challenge, and needless to say, in the process, I felt that the knowledge I was acquiring was giving me a modicum of decision-making power, power over my future, and a way of communicating with others in the same boat. Is that feeling real or illusory? This is one of the questions threaded in a ghostly form through Diary of a Detour. The more I delved into the scientific, the more I found that awe was being ruffled by skepticism. The skepticism is not ranged against science as such, but against the way science can be used and against the extreme medicalization of cancer in our culture. By medicalization I mean the impulse to describe its causes, origins, trajectories, and treatments in primarily medical terms. What other language might there be? What ways of evoking the feelings and sensations that one might experience; what ways might there be to think about cancer not in terms of a war waged by the wonders of medicine against a foreign invader, but as something that arises in the body and is a part of life? How to shift or at least shake up the idea of living with a chronic illness, to think about living itself as a chronic condition, not a fortress armed against death?

In a fanciful rather than scientific gesture Plato defined the human being as "a biped without feathers." It tickled my fancy, this aphoristic description of the human being. There are occasions when I experience myself becoming chicken, and there are times when a chicken takes it into their head to become human. This makes for stories. But it also provokes me to think about the process of domestication and how this relates to boundaries, parameters, borders. I was born and grew up in Zimbabwe (though then it was Rhodesia) and lived for many years in Australia. I now live in the U.S. city of San Diego, a city on the border with Mexico, where I also spend time. This peripatetic life has nurtured both a yen for travel and a meditating on borders. Where does one country end and another begin, what is it that makes a difference between a well body and a sick one, how do you distinguish between species that interact and depend on one another in intricate and complex ways, how do the dead speak to the living? During domestication humans change animals and plants through artificial selection, but the process of domestication also changes us, genetically and socially. In some ways my dance with CLL is akin to this reciprocal process of domestication. It begins in wildness

and evolves into an attempt to tame and contain the dragon. In some ways the attempt works, in other ways, not. The CLL also tames or shapes me, alerts me to new modes of inquiry. Similarly, I make use of chickens, but as is often the case they turn out to make use of me, to shape the writing and thinking in ways I did not anticipate or envisage.

Being a chronic condition, CLL doesn't go away, but there are quasi remissions when you can up sticks and fly away to new adventures. The book itself can take wing, and on occasion it flies away from San Diego to places far and near. But then there are missteps, the symptoms creep back, gradually the fatigue begins to permeate your every moment, you succumb to infections, some virulent, you dodge death threats, and you realize there's no getting off the bus. On the other hand, here I am, after fourteen years, still going. In the meantime various friends or people who have inspired me on the CLL trip and side trips have died—some suddenly and without warning. The first to go was my friend Miriam, who died after I was diagnosed but a few months before my first treatment began. I wrote a small piece when she died, and I include it in the book, even though it falls outside the time frame, because I learned from her, and from writing about and to her, not exactly how to face death but how to live, how to get on with life. The book is punctuated by addresses to or about friends or people, dead and alive, who have at some stage mattered to me or who shared the journey or parts of it. If there are hungry ghosts haunting this book there are also spirits who inspire. There is no ravine separating the dead and the living, health and illness, animals and humans, chickens and microbes. And so dead ones and animals and plants animate this writing as much as humans and those alive.

The sequence is ruffled because it is not in fact a sequence; or, as one might say, it is not, in the end, the illness that determines the trajectory. Correspondingly, the map encompasses more than lines. The squiggles, veers from the straight and narrow, ideas that grow in the writing and careen into obsessional cannonballs—all these excursions embody the energetic impulse of the detour. In the end, and from the beginning, it is the detour rather than the journey that embodies and mobilizes the way time is experienced in this book. Hence: Diary of a Detour.



#### CHAPTER 2. THE TIME IT TAKES (BY WAY OF AN INTRODUCTION)

5 Plato defined the human being Page Smith and Charles Daniel, The Chicken Book (Athens: University of Georgia Press, 2000), 16.

#### CHAPTER 5. EVENTS UNFOLD IN THE SNOW

- 13 the book Miriam had finished Miriam Hansen, Cinema and Experience: Siegfried Kracauer, Walter Benjamin, and Theodor W. Adorno, ed. Edward Dimendberg (Los Angeles: University of California Press, 2011).
- "in a photograph a person's history is buried..." Siegfried Kracauer, The Mass Ornament: Weimar Essays, ed. Thomas Y. Levin (Cambridge, MA: Harvard University Press, 1995), 51.

#### CHAPTER 7. WHY CHICKENS, OR HOMAGE TO GLORIA

- 18 "I remained loyal, as a man would to a bride..." E. B. White, "The Hen (An Appreciation)," in The Second Tree from the Corner (New York: Harper and Row, 1984), 235.
- 21 Backyard chickens dumped at shelters when hipsters can't cope, critics say Jonel Aleccia, "Backyard Chickens Dumped at Shelters When Hipsters Can't Cope, Critics Say," NBC News, July 7, 2013, https://www.nbcnews.com/healthmain/backyard-chickens-dumped-shelters-when-hipsters-cant-cope-critics-say-6C10533508.

#### CHAPTER 8. BOOMERANG

Akos's book is about plastic money Akos Rona-Tas and Alya Guseva, Plastic Money: Constructing Markets for Credit Cards in Eight Postcommunist Countries (Stanford, CA: Stanford University Press, 2014).

