

Sara Greenslit

## **If**

During the fourth year of veterinary school, I rotated through the required clinic weeks of small animal internal medicine. When finished, I said to my professor that it seemed like one-third of the cases never got a definitive diagnosis, a crisp answer. She shrugged. She expected this. She was in the intellect-pod of people comfortable with ambiguity.

I'd like to think I am too. But I cannot even pretend this for myself.

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At thirty-eight, I found a lump in my left breast. I spent a month imagining my unraveling, framed by moments of clarity that I was frothing myself up about nothing. I told myself, Stop perseverating. Then I went to the doctor and the tests began: ultrasound, mammogram, breast MRI, stereotactic core biopsies.

My breast cancer diagnosis came in as Stage IIa, but the tumor type blurred clear treatment recommendations. My case went up before the oncology board, and so: Let's treat it like it could fall into the worse category, due to my younger age, due to them knowing about cancer's individuality, its trickster malleability. Mastectomy, four rounds of chemo, five years of daily estrogen-blocking drug, tamoxifen.

I declined a few treatments due to the possibility of graver side effects: complete axillary lymph node removal (lymphedema), more aggressive chemo (heart failure), and chemically shutting off or surgically removing my ovaries (sudden, severe hot flashes).

We cannot know if I elected the right treatments, or if I was over-treated. And if cancer returns, were the choices faulty, or would it have returned regardless?

My notebook from cancer time: "And then there's the wiggle-waggle of percentages. Maybe my risk of getting metastatic cancer is greater than 10%. Doctors use risk calculators to help make decisions, but then nothing is guaranteed. It's oncology. To quote Onc Doc, 'Estimating your risk of distant recurrence is a bit difficult, given some of the peculiarities we discussed: no invasive disease found in the breast,

a micromet lymph node. All of our models probably vastly under or overestimate your risk.””

A year after the initial treatments, the breast cancer categorization system was revised. My stage was downgraded to Ib.

Does this shift in stage negate my previous emotional and physical stresses—my tears, my maw of fear, my agitation at chemo and surgery’s side effects—which were shaped by what we thought it was?

And what is the difference between how we handle doubt during diagnosis and treatment, and how we exist in continual uncertainty, after the fact? (You cannot go back, you cannot go back—)

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In *What Doctor’s Think*, Jerome Groopman recounts a study where 10-15% of diagnoses were incorrect at autopsy. He sifts through the thought patterns of error-categories within medicine. We ignore details we don’t like, we chose the wrong path too early, we cling to an answer that doesn’t quite fit, we don’t have enough information. And despite all the training, our eyes sometimes fail at finding breast cancer on mammograms, heart attacks on EKGs, lung cancer on screening x-rays.

*Lo, perfection, a great foe.*

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You treat the most likely thing with the information you have available, and in my job it often depends on the pet owner’s finances. *It would be best to take an x-ray and urine culture to rule out a bladder stone and infection as the cause of your cat’s bloody urine, but we can try X first.* (The medical records read, “rads, u-culture d/c, O elects med mgt.”) *Your dog may have a spinal tumor, only an MRI will tell you, but what will you do with this information? Will you elect palliative care, or is surgery or radiation an option for you?*

And it comes down to this too: what kind of clinician am I? Did I miss something on the exam, did I not ask the right questions? Was I under-caffeinated, or grieving my own losses? Was I distracted?

Atul Gawande, writes in “The Case of the Red Leg” in *Complications*, how variables and instinct influence catching a serious illness. For him, it was a necrotizing fasciitis case (flesh eating bacteria), which has a

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high mortality rate: “[the patient] would have been treated completely differently depending on where she went, who she saw, or even just when she saw me (before or after that previous necrotizing fasciitis case I’d seen; at 2 am or 2 pm; on a quiet or busy shift). She’d have gotten merely antibiotics at one place, an amputation at another, a debridement at a third. This result seemed unconscionable.” The initial evidence pointed to a 5% risk of having the disease, but if the medical team was wrong and treated her leg like basic cellulitis with antibiotics, the fatality rate was 70%. In the end, they did four surgeries in four days removing dead tissue, saving her leg and her life. “It is still not apparent to me what the clues were that I was registering when I first saw [her] leg. Likewise, it is not obvious what the signs were that we could get by without an amputation. Yet as arbitrary as our intuitions seem, there must have been some underlying sense to them.”

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During pathology courses in vet school, I was astounded by all the ways the body was bent on malfunction, failure, the slide toward ruin. Take any cell in the body—toenail, iris, red blood cell, bladder wall: it can mutate to cancer. Throw in congenital malformations (pulmonary and aortic great vessels swapped at the top of the heart? born with one central eye?), the list blooms. Want to see how ageing destroys your cartilage, your joints? How many organs can melanoma spread to? I couldn’t stop imagining all the permutations, I could not keep up.

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When my father got sick, I felt pressed under a large stone. I saw his cancer in the center of everything, and stellate worries and questions burst out in flares. How? Where? When? Afraid, I focused on the uncertainties of suffering, on dying. Things I thought we could control by having more information.

I tumbled thoughts over and over, an attempt to smooth an intractable pebble: what if the doctors had found my father’s recurrent prostate cancer before it spread to his pelvic organs and cracked his hips and femur? Would he have agreed to chemo, and would it have ruined his days? He was stoic, yet his weight loss, daily vomiting, and persistent pain burned untenable.

When I asked how he was doing, he would say, Fine. When I asked him what he knew about his illness, he said, They don’t tell me anything. If I asked, Are you on antibiotics? Do you have a fever? How

many screws are in your fracture?, he'd say, I don't know.

He chose to stay in the state of unknowns. I opted when diagnosed with breast cancer to read and read and read. I still felt I was about to fail an exam for which I could not possibly fully prepare.

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In *Being Mortal* Atul Gawande formulates four questions to ask the dying:

- What would they like to see happen, short and long-term?
- What are their biggest fears and concerns?
- What are their most important goals?
- What trade offs are they willing to make?

These questions work with other states of medical ambiguity as well. I cannot ask my patients what they want. I have to ask what the owners hope for their pets instead.

My brother asked my father these questions but did not tell us what he answered. Did he hear my dad, or just what he wanted to hear? What is it we all want to hear?

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Here's a caveat for the vet school cases that resulted in no specific diagnoses: these were complicated referrals, the puzzles were murky. The complex and expensive follow-up tests did not guarantee answers. They helped cross things off, like a reverse to-do list, the tally of rule-outs. Not This, not That. They did not come up empty-handed: negative definitions are still definitions.

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During the first summer of vet school, I suddenly began tumbling to the left. My vision blurred, the ground fell away. I couldn't read a computer screen, I couldn't walk without hitting the wall.

I saw two neurologists and an ear nose & throat specialist, had a CT and two MRIs, hearing tests, a brain stem response test, blood tests (but no spinal tap), and an electromyogram.

Rule out acoustic neuroma, rule out stroke, brain tumor, multiple sclerosis, inner ear inflammation, otolith displacement, Meniere's, the

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list goes on (DAMNITV: degenerative, anomalous, metabolic, neoplastic, infectious, inflammatory, immune, trauma, vascular . . .)

Rule in idiopathic.

My second neurologist said the cause of my balance disorder was unknown but it was not progressive, it was not fatal. He seemed mildly impatient with my despair at my dizzy daily life. Many of his patients had terrible, obliterating conditions. So he showed me his own MRI to compare his brain's multiple sclerosis lesions to my clean films. Then he gave me some direction: "You will be all right," he said. "You have things to do." He said I would not stay home and go on disability.

And many years later, thinking of his forecast, it felt like being startled in late winter—it had been dark for so many months and now it was still light out at 5 pm.

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What are we supposed to do with the not knowing, the chasm of choice when we cannot have all the information to guide us?

Clients ask: How do you know it's the right time?

Some days it's clear when euthanasia is the best path out of suffering. Some days it is not straight-forward.

My seventeen year-old Sasha cat disintegrated over months, losing more weight despite normal blood work, wrists bent with arthritis, her dementia so thick she'd forget the wet food right in front of her. I called my vet friend, *Come over*. I called her back, *Don't come*. I called her again a week later.

Will it be too early, or did I wait too long? Will we look back with regret or relief?

My old shepherd, Murray, stumbling in the kitchen at breakfast, was paralyzed and down in the yard by 2 pm. Friends came over to say goodbye, and I euthanized him before dinner. We drove out to our friends' farm for his burial that evening.

I have a picture of him that morning, looking out the back door in his red harness with the handle to steady him. His back end had been failing, we had been helping him steer.

My first dog, Ouzel, collapsed after slipping on the ice. By the time we got to the ER he was in shock from internal blood loss from a ruptured tumor in his spleen. I chose euthanasia over risky surgery and two to three more months with him. He died ten years ago, and I still wonder: should I've done more?

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A long tendril of a dusty road, going and gone, until its eaten by the horizon. I can't tell what's down it, amidst the gravel. I stand and stare, hand up to block to the sun, and it's just itself, rolling out in front of me.

I've had a recent mammogram and a breast ultrasound to look for the new source of bloody discharge, eight years after my cancer treatment. No calcifications, no ductal warts, no dilated ductwork. Still. I look up to re-remember what positive predictive value and sensitivity means. I think about false negatives. I schedule a recommended surgery referral. Did the radiologist say, Bloody discharge is never good? Or never normal? It was a negative definition, layered over negative test results. My Ifs.

It's all uncertain. At work, a cat's nasal discharge becomes a brain tumor found on CT. A nine-year-old petite pit bull comes in a large box, dead from head trauma from a bus, her family stunned into sudden grief. Then the next week, three packages of pastry, one of muffins and two of cupcakes arrive at the clinic on the same day.

I sing a wordless song into my dog's ear. She turns to me. Sometimes when I drive, she stands up, and puts her small feet on my sternum and looks into my face. I inhale her scent. These moment are concrete.

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I'm looking for something solid in the convolutions of ambiguity. When I am unsteady, I go to books. Maybe there's a way to get a firmer grip on that slipping rope.

In *Attending*, Ronald Epstein says we have to let go, ride out our anxieties of not knowing. Be open to waiting, the unfurling of information over time. He says sometimes we have to work inside and with persistent ambiguity. And these unknowns may shift, morph into different categories, change into differing complexities. Fluctuate, ripple, tremolo. How do we steady ourselves?

I fight it, this holding onto nothing in hopes of seeing the something, hidden there.

Give me something to write down, some directions to follow.

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In *How Doctors Think*, Groopman recommends to doctors, for patients, how to steer a correct diagnosis:

Tell me the story again, as if I had never heard it, from the beginning.  
Tell me what is really frightening you.  
What else could it be?  
Is there anything that doesn't fit?  
Is it possible I have more than one problem?  
When the doctor says, "I believe you when you say something is wrong, but I haven't figured it out," take the doctor's referral.  
Doctor should avoid saying: Nothing is wrong with you.  
Doctor should acknowledge your feelings.  
Doctor should talk context of your treatment: where, when.  
Not all meds work the same for all people; we all have different biologies.  
Treatment should be free from financial gain and corporate influence.  
Doctor should not rush.

I am looking at this list, summarized in my diction, and I wonder what else I could use these instructions for?

There are many ways to get lost.  
Should we stop, exhale, feel our feet?

*Tell me what scares you. Tell me your story from the beginning.*

