Fine, Thanks

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This doctor, yet another one I hoped would be able to help when others couldn’t, calls me “Sweetheart.” Is there anything more patronizing? He pats my shoulder. He thinks I’m crying because I feel lousy and he can’t figure out why. I’m crying out of fury that he, and everyone in his office, treats me like a child, like I don’t have a brain and a life and better things to do. And fury that I’m crying in front of him. And, yes, a little bit because I feel lousy.

“Sweet” and “heart.” As if being ill makes me gentle, docile, harmless.

He recommends meditation. Yoga. Vitamins. A daily nap. Perhaps increasing my fiber intake? He is looking toward the door, and I am sitting on an exam table in a stupid paper towel like a piece of meat ready for processing.

Ah, yet another doctor I won’t be returning to.

I’m not sure how to live this life of chronic illness. Ghosts of pioneer ancestors moan at me from the freezing plains of Wyoming: “Buck up, you wimp.” I seesaw daily between pushing myself through tasks, determined not to let others down, and shaming myself for playing the martyr. There’s no steady ground here. What is my duty?

I have always been a “good girl,” a rule follower, righteous, reliable. I do my duty. Being sick has therefore put me in a pickle because there is no knowing how to be a “good girl” when I am sick.

Here’s what I’ve picked up, from who-knows-where, about the duties of a “good” sick girl.
First of all, a good sick girl never gives up. She would never accept a diagnosis of “chronically ill” just because one doctor in town thinks he's solved the mystery with some vague, catch-all diagnosis. She owes it to herself and her family to push on in search of a cure, trying doctor after doctor until she sees progress.

Except, of course, when money’s tight (which it always is). No, a good sick girl accepts a diagnosis with serenity and would never waste her energy and her family’s money pursuing a more accurate diagnosis or, heaven forbid, a miracle cure.

Except, of course, for miracles that come from God. A good sick girl always seeks those.

Except, of course, when it’s God’s will that she not be healed. And if that’s the case, she would never murmur or complain.

Except, of course, to her true friends, who want her to feel free to vent, free to call when she needs help, because when they drop off their casseroles, they’ll never notice how lazy her kids are or how amazing it is that she’s somehow able to keep up her blog and get her hair highlighted even though she can’t seem to get her floors mopped.

A good sick girl appears at her doctor’s office clean and neat because to appear too shabby shows she is wallowing and doesn’t really want to get well.

Except, of course, she wouldn’t appear too neat because, really, how sick can she be with that ironed shirt? She needs her doctor to take her distress seriously.

A good sick girl trusts her doctor, who obviously knows best. She follows his instructions exactly because that proves to him and the world that she sincerely wants to get well.

Except, of course, that doctors sometimes make mistakes, so she researches everything for herself. But she would never Google her symptoms because that’s a sign of hypochondria and negative thinking. In fact, she avoids negative thinking like the plague (which she probably doesn’t have), and so she would never join a “support group.” Instead, she surrounds herself with healthy, positive people.

A good sick girl would never pay money for anything not FDA approved or chase after practitioners of alternative therapies because those people are quacks, simply out for her money.

Except, of course, for that guy who really helped Aunt Fern. He’s worth trying, and if the sick girl refuses to try, she’s closed-minded and doesn’t deserve to get well. She’s obviously giving up.

And a good sick girl never gives up.
I don’t know where I got these ideas. I’ve never felt judged by my circle of family and friends; nothing they’ve said or done has made me think they are judging me.

But I can’t deny the expectation of self-sufficiency that is part of my hearty Latter-day Saint culture, like all the ward council discussions on how to help the needy, which occasionally include the debate about whether Sister So-and-so has been “taking advantage.” On the street level, the wards I’ve belonged to have been generous and nonjudgmental. But there is a pride among us Latter-day Saints in the fact that our welfare system encourages productivity and independence even as it dispenses aid. We don’t mind helping the needy, but they’d better be truly needy, deservingly needy, and they’d better be doing their best not to remain needy.

At the same time, I both worry that I am not truly needy and fear that I might be.

I spend a lot of time in bed or a recliner. I am lucky to have been blessed with a personality that enjoys being sedentary. Many of my favorite activities can be done from a recliner—reading, writing, watching movies. I’ve picked up a few new ones since getting sick: knitting, meditation. And family history. Recently, sifting through charts and records for people who’d left their bloody signatures in my genes, I found a sixth-great-grandmother of mine. Tucked into a corner of a census under her husband’s name, she is listed simply as “Rebecca.” Under the “Profession” column, where other women’s records say “wife” or “mother” or sometimes “nurse,” the census taker has scrawled the word Invalid. As her profession. As the one word to describe what she did with her life. She, an entire person, living day after day of life, mornings followed by afternoons, followed by evenings and nights, was simply an invalid. Certainly she was a mother—several children are listed below her name—but the census taker has decided that this word, more than any other, defines this woman and her contribution to the world.

Invalid. Not valid.

I know you’re curious. So here are some cures I’ve tried (most of which came highly recommended by acquaintances whose lives have been changed by them): Eating “clean.” Homeopathic drops. Juice cleanses.

Oh, and two more things: prayer and faith.

Most of the time, I’ve accepted that I’m probably going to feel like this for the rest of my life. But occasionally I stumble across a story of a new miracle cure I haven’t tried. I’ll overhear someone talking at the grocery store, maybe, about a chronic illness to which she has finally found the answer, and now she feels better than she ever could have imagined. Or I’ll meet someone at a mutual friend’s house who, maybe not even speaking to me, will tell about her sister’s rejuvenation after trying out a new doctor who “finally really listened.” And for a few days I will prod this new idea in my mind the way you might prod roadkill with your foot. Is it alive? Is it for me? Or should I leave it alone? Because it’s my duty to be open; anything I encounter might be God, right?

Always, then, the decision is: jump back into the hunt, the gamble of hope and money and time, or make peace yet again with the fact that this is my life? These days I almost always choose the second option, knowing I am much more likely to end up with it anyway, at the end of another exhausting journey.

Is this faith, or a lack of it?

In the beginning stages of any new friendship, I wonder when and if I should tell my new friend about my illness. I think about that word, invalid, and then I usually choose not to. But while I’d like to be considered a whole person, separate from my illness, I can’t deny that any account of me isn’t complete without an accounting of the long, pea-green, seasick afternoons in the recliner, listening to life going on outside my window, envying the miserable people on talk shows who, while full of other problems, still have energy enough to jump around the stage. Days of feeling like gray mop water—a big part of my life, a part of my biography, but impossible to document.

I guess this essay is my effort at documenting.
I have studied the scriptures for every reference to health, healing, illness, and the body. Most of the time, health is mentioned in connection with a miracle of healing. Miraculous healing happens. Of course it happens.

Early in my marriage I gained a testimony of the power of priesthood blessings. After a struggle with infertility, my first pregnancy was precarious. Some unusual and, apparently, unhealthy hormone levels caused my doctor to pronounce the pregnancy “nonviable.” He recommended a dilation and curettage procedure (a “cleaning out of the nonpregnancy”) so that we could try again. But in a priesthood blessing, my husband promised that the baby would survive and be fine. I called the doctor, asking again how sure he was that this pregnancy was no good, and he said, “Well, 99 percent.” But a one-percent chance and my husband’s blessing words were enough to make me refuse the procedure.

Eight months later, my son was born, perfectly healthy. As my doctor stitched me up, I asked him, “Shall we name this baby Little One Percent?” I wanted a reaction from him—a big reaction that acknowledged the pink and mewling soul I held—but he said nothing. But I held that baby, and held my faith in priesthood blessings.

So, of course, in the early years of this long illness, I sought blessings. In these blessings, my husband always said that this was a “blessing of health,” but he didn’t expand on what that meant, elaborating rather on the great things I would learn as a result of this experience and the ways it would bring me closer to others.

What does “a blessing of health” mean? I pestered him to explain what it meant, and he wasn’t sure. Years passed, and I didn’t get significantly better. But I didn’t get worse. Was that what it meant?

I think about priesthood blessings. Is the healing power in the actual words? Or is it just about guessing what God has planned anyway? Maybe my husband has been using the wrong wording. Maybe he isn’t supposed to promise me health but rather to actually deliver it. Maybe he is supposed to say something exact like “Be healed!” and then it would happen. I tiptoe around the subject with him. I don’t think I’m supposed to tell him what to say. I throw it out there as a possibility. He says, “I say what I feel I should say.” I drop the subject.

Six months or so into my illness, I was released suddenly from my calling as Primary chorister. I had been in the calling for only a year and was just barely beginning to enjoy it, to relax with the kids and be flexible
with time (see “be less perfectionistic” above). It was the first time I had ever been released from a calling before I was ready.

It’s true that Sundays were exhausting for me, that I came home from church and collapsed into bed. But it’s also true that on Sundays I saw God’s hand in my life. I would pray before Primary that I would be able to make it through singing time, that I wouldn’t have an attack while I was teaching the children, and I know that God helped me, every time.

I suspected that the release wasn’t God’s doing but rather a mistake caused by the mortal weaknesses of the Primary president (my visiting teacher) and the bishopric counselor. Probably, I guessed, they had used their knowledge of my illness (I had no illusions that I wasn’t being discussed regularly in ward council) to make the logical decision that I “needed a break.”

More than just suspecting, I needed to believe that the release wasn’t God’s doing. Because if it was, it meant something: it meant that I wasn’t going to get better soon, that healing wouldn’t be a quick thing.

Desperate for reassurance, I went to the bishopric counselor, in tears, and begged him to tell me the truth: was this release inspired?

He sputtered. What could he say? Another woman had already been called, was already leading the singing down the hall that I could hear in the background as we sat together on a couch in the foyer. He finally said, while looking away, that yes, he did feel that this was an inspired change. I went home from church and got into bed.

When I was twenty-three, my mother died of cancer. She had fought it the first time, doing the whole chemo thing. Then she was supposedly cancer-free, and her hair grew back, and all was good. And then, two years later, it wasn’t. When the cancer came back, she didn’t fight it, by which I mean that she didn’t do surgery or radiation or chemo again or try any of the alternative therapies people suggested but moved right to comfort care to make the best of the time she had left.

And we didn’t blame her. We had seen how miserable the fight was. We knew that the odds of beating it now, when the first time hadn’t worked, were extremely small. It seemed a reasonable choice. Even—dare I say it?—a healthy choice.

During this time, the time of her dying, my friend Henry’s father was newly diagnosed with cancer. Henry came to talk to me about my experience. When he heard that my mother was not doing chemo again,
was simply moving toward hospice, he was shocked. “How could you let her do that?” he asked. “Don't you have any faith?”

Before I could answer, he continued: “I have faith. I have faith enough. I know my father will be cured.”

The conversation unsettled me. Were we giving up too easily on Mom?

Her dying took about a year. And a year or so after that, after I had moved to a different town, I heard the news that Henry’s father's treatments had been unsuccessful—he had died. I did not ever ask Henry about it—what could I have said? What could he?

A year or so into my illness, I thought I'd probably die. It didn’t help that one doctor told us he strongly suspected I had a form of cancer (which was finally ruled out after many tests). And of course it didn't help that my mother and her mother had both died young of cancer. The point is that I was pretty quick to abandon faith for fear. And I’m sure my anxiety made me sicker, at least until I realized that I wasn’t dying, that things didn’t seem to be getting any worse.

The thing is, I do have a story of faith. Although I’ve been frustrated at the lack of stories in the scriptures about sick people who aren’t healed, I have always been grateful for the story of the people of Alma. They were enslaved and wanted to be released. They had faith enough to be released. But instead, at least for a while, God strengthened their backs so that their burdens felt light. Of course, eventually they were also led out of slavery. I know that eventually I will be, too, even if that eventually happens after death. But also like the people of Alma, I have felt my burden being made light at times. For example, during a time when I was quite debilitated, I one day realized that we had been experiencing an amazing period of time without household challenges. For about two years, none of our children had had problems at school or in their social or spiritual lives. Nothing around the house had broken down—not the car, dishwasher, garage door, water heater, or lawnmower—nothing. For years. I knew, in that moment, that this had been God’s doing, that he had known we couldn’t handle anything else right then.

At other times, I’ve found that while God hasn’t made me well, he has given me enough strength to accomplish small, immediate duties when I have asked particularly for it. Like the Primary music I mentioned above. “Just let me be able to get through my child’s parent-teacher
conference,” I might pray. Or, “Just let me make it through this drive to this doctor’s appointment without having an attack on the freeway.” These are my mini-miracles of healing, and I acknowledge them with gratitude. They tell me that God is there, walking with me. And when I am firm of mind, I know that that is enough help, moment by moment, to get me through my whole journey.

I wish I could remember this all the time, but I don’t. I forget. I forget when my family goes hiking and I have to wait in the car. I forget when the young moms in the ward talk about the relay race they are running together. I forget when my seventy-five-year-old mother-in-law offers to carry a heavy box for me. I forget when, from my recliner once again, I hear the front door slam as my children come home from school and fix themselves a snack, and I wait, staring at the bedroom door, hoping they’ll remember to come upstairs to greet me.

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