Cure by the Spoonful: Why Your Friend with a Chronic Illness Just Can't Swallow Your Advice

ANYONE WHO HAS EVER had a chronic illness or chronic pain has heard it a hundred times:

> Oh, you have X? My cousin had that, too! She cut out white sugar and the pain went away.
> I used to wake up so tired every day, but then I stopped eating gluten and now I run three miles before breakfast.
> I just read an article about this woman in Australia who cured her multiple sclerosis (MS) with a super-healthy plant-based diet.
> You know what you should try . . .
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It's a phrase we dread. Sometimes what we-with-disabling-chronic-conditions should try is yoga or meditation—a suggestion that is equally irksome but should be the subject of its own essay—but more and more often, "what we should try" is related to a particular regimen of diet and eating that will return us to the presumably symptom-free life we led before becoming disabled. And it will do so "naturally"—that is, without traditional medicine.

It's not that we don't appreciate it when friends and family, or even kind strangers, take our suffering seriously and actively attempt to participate in its amelioration. Most of us have tried many of the things people have suggested we try. (Okay, sometimes I don't appreciate it when a random person in a grocery line sees my cane and lectures me about the dangers of dairy while glaring at the chocolate ice cream in my cart.)

It's just that most of the time, suggestions about "what we should try" aren't really about us and our well-being at all. Just like the conventional medicine that diet-based, "wellness" approaches to chronic illness attempt to supplant, most of the time the non-sick person offering their wisdom has not really listened to what the sick person has said about their condition, nor have they considered the entire socio-psycho-biological context of the person's sickness—that holism that is supposed to be the hallmark of alternative healing systems.

I have no doubt that eating fresh, high-quality food is good for everyone and that we could all use more of it. Everyone. Everywhere. But after more than ten years as a person with disabling chronic pain and a slew of complex, interlinked conditions, I can also say that, despite the growth and proliferation of "food as healing" diet and lifestyle plans—with anti-inflammatory, Mediterranean, Paleo, and Keto-derived books, websites, products, and social media spaces now worth billions of dollars—for most people I know living with chronic illness and pain in the United States, the relationship between the way they eat and the way they experience their bodymind is complex, changing, and surely not reducible to any one doctor or dietician's prescriptive approach to food.[1]

Even after my own health struggles forced me to embrace a demanding form of dietary restriction—the dreaded "low histamine" diet—I find most unsolicited suggestions about "what you should try" vexing at best and, at worst, able-ist, fat-phobic, and scientifically questionable.

Let me put this another way: you may mean well, but you are not helping.

I spent years feeling confused about how I should relate to food.[2] Of course, like everyone else, I had read stories about people claiming to have cured everything from eczema to Parkinson's with a particular diet regimen. In northern California we talk about diet experimentation the way other people talk about the weather. I heard neighbors chat about how their arthritis no longer troubled them once they gave up gluten; how their child's ADHD vanished when they cut out

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sweets; how joy was to be found in a gut steeped in home-fermented kombucha. These conversations made me nervous and defensive, but I listened. I always thought I should be doing something I wasn't. Worse, I feared that maybe I was failing to get better when I actually could just because I didn't have the willpower to avoid cookies when I was finally hungry or coffee when I was too tired to cook.

It's not that I never tried. I did attempt to track my diet at various times, or to give up certain foods. But I could never find a connection between things that I ate and my pain level or degree of neurological dysfunction (with the exception of alcohol, which so obviously created joint pain that I gave it up in 2015). I could eat the exact same thing two days in a row and have completely different experiences of my pain and muscle control.

Complicating the situation even more, one of the side effects of both severe chronic pain and some of the medications I take to manage that pain is loss of appetite. I often simply am not hungry; the thought of food is even nauseating. Not to mention that debilitating chronic pain makes jumping off the couch to chop loads of fresh vegetables and boil your own bone broth basically impossible, unless you have the financial means to outsource that labor, which I do not. Lots of days I am lucky if I can get any food in my gob at all—so if it's a white-flour bagel with cream cheese, so be it. Some days, that's a win.

I think this is something my food-enthusiast friends need to hear: the exhortation to dietary restriction as a path to cure reflects and actively creates a contradictory relationship for people with disabilities to the field of nutritional research and any potential health benefits of dietary changes. It's a coin with two sides. On one side, cure-through-food encourages the kind of decontextualized, neoliberal focus on the individual and her "choices" that has been amply and ably critiqued elsewhere because it presumes a cis, white, able-bodied, family-ensconced and monied subject who has vast fields of choice (Brenton 2017; Guthman and Caldwell 2014; Hunt 2022). Cure-through-food is a form of consumption in which food and how it is eaten signal differences of character, of "good" versus "bad." Every suggestion effectively creates the suggester as morally superior to the (implicitly) weak, lazy, less-than disabled listener (Dean 2022; Vidali 2022).[3]

On the other side, because incredibly lucrative cure-through-food systems focus on food lists and making good choices at the expense of exposing and changing structural barriers to food access *and preparation*, most people with disabling chronic illness in the United States today are simply unable to follow complicated diet protocols, even if they want to. The current political economy of food actually bars our access to ways of eating that very well might help ease certain forms of suffering or support processes of bodymind repair. Food-to-cure is expensive and time consuming, demanding two resources that disabled folks are less likely than any other group in the United States to possess: money and energy.

It's important to understand how this moral discourse is created and functions not only among evil Big Food and Pharma but by those invested in healing and wellness, so that we can see just how insidious it really is. Building on work in disability/mad studies, fat studies, and critical food studies, in this essay I use my own experience as a disabled woman with chronic pain to examine the contradiction at the heart of cure-through-food regimes. My sense that there was something deeply problematic (and scientifically dubious) at the heart of these approaches kept me out of their orbit until severe adult-onset food allergy compelled me to make diet changes. Though I have seen positive benefits from new ways of eating, this essay is more about why I refuse to be evangelical about any one way of eating than it is about the benefits of my current dietary restrictions. Rather than worrying about what your friend should do, I recommend that we all take up a much broader, disability justice–based approach to questions of food, wellness, and healing.

Food justice movements need to embrace disability justice if they are ever to make truly radical change for our communities. This means, first, the recognition of base realities such as the fact that people with disabilities live in poverty at twice the rate of people without disabilities (Goodman et al 2017); that disability is a huge risk factor for poverty; that poverty causes disabilities of many kinds, from illnesses resulting from chronic stress to those such as asthma and heavy metal poisoning, which can result from unsafe air and water, to a basic lack of medical facilities and care (Goodman, Morris, and Boston 2015; Ingstad and Eide 2012). When taking an intersectional approach to disability and race, the problem of "food deserts" (i.e., lack of supermarkets selling fresh food or inadequate transportation to access supermarkets) is amplified.

Embracing disability justice means rejecting the assumption that there is one normative bodymind to which we should all aspire. It means centering an intersectional approach in which disability is seen as a meaningful vector of difference with highly material consequences, which cannot be separated from other forms of difference such as race, gender, class, sexuality, and geography. It means working with disabled communities to educate the non-disabled about access as an ongoing process—not a one-time tick of a box for dietary restriction—that requires much more *deep listening* than advice giving.

My Inedible Alphabet Soup

I live with a condition known as hypermobile Ehlers-Danlos Syndrome, or hEDS, a genetic connective tissue disorder that affects the body's ability to produce collagen. hEDS is one of thirteen known types of Ehlers-Danlos Syndrome; it is the most common variant.[4] Because collagen is a structural building block for most tissues of the body, it is less appropriate to see hEDS as a disease than, as Dr. Pradeep Chopra puts it, a "form of the human body."[5] But it is one that is often disabling.

hEDS can produce an amazing array of symptoms in almost every system of the body. For the hypermobile type, the major clue is usually joint instability—wobbly collagen in our fingers, wrists, elbows, shoulders, hips, knees, ankles—which can cause frequent dislocation, or "subluxation," as well as the wide-spread joint pain that accompanies these daily traumas.

But there are many hEDS-linked comorbidities due to tissue fragility that do not directly impact the joints themselves. These include ubiquitously low blood pressure and difficulty with blood pressure fluctuation in the form of dysautonomia or POTS (postural orthostatic tachycardia syndrome). hEDS bodies also seem particularly sensitive and reactive to the world around them and tend to have or develop post-viral ME/CFS (myalgic enephalomyelities/chronic fatigue syndrome), Lyme disease complications, Complex Regional Pain Syndrome (CRPS), multiple chemical sensitivities and other forms of environmental illness (MCS), mast cell activation syndrome (MCAS), and digestive problems of all kinds—irritable bowel, gastroparesis, hyperemesis, hypoglycemia. Then there is the creativity of the hEDS nervous system, which is capable of producing severe pain even without a specific injury; muscle spasm; loss of speech; brain fog; seizures; and generalized neuromuscular disorder that may be linked to inherent neuroprocessing issues, particularly with dopamine (it has also been linked to Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD).

In essence, hEDS can affect everything the bodymind experiences and does.

Most of us with hEDS live in an "alphabet soup" of our own personal blend—a long list of comorbidities that affect us every day, but the flavor of that soup differs from person to person. My hEDS is a particularly painful and nervy one, with lots of joint injuries thrown in, so my alphabet soup includes Complex Regional Pain Syndrome (CRPS) and a rarer hEDS complication, dystonia, which includes hemispheric paralysis, tremor, and spasm. But I also have periodic bouts of POTS and fit some diagnostic criteria for ME/CFS. Recently I have struggled most with Mast Cell Activation Syndrome, or MCAS, my body's over-excitable histamine response to just above everything on the planet. There's so much going on at any one time that it's hardly surprising even my closest family and friends don't entirely understand the full picture.

I am, in sum, a Spoonie. This is a term that people with disabling chronic illness often use to identify themselves and each other. It derives from a self-published online essay by Christine Miserandino called "The Spoon Theory."[6] Miserandino lives with lupus and found that she had a hard time explaining to loved ones what it's actually like living with an illness that requires constant attention, saps energy, and waxes and wanes unexpectedly. "The Spoon Theory" describes a moment sitting in a diner with a friend when Miserandino hits upon a way to make the struggles visceral. Grabbing up a handful of actual spoons, she asks her friend to imagine a life in which each activity, from making breakfast to taking a shower, requires handing over a certain number of spoons. But, Miserandino explains, we are only given so many at the beginning of every day. She asks her friend to narrate her typical routine. Surprising things require spoons, like simply waking up if one slept badly or hair-washing in the shower. Miserandino's friend quickly realizes that just to take care of the bare essentials of life she'd be out of her allotted spoons very quickly, and probably unable to feed herself by dinnertime. This is the point of the experiment. The friend experiences a flood of empathy. Miserandino is pleased but reserved about her friend's epiphany, saying simply "I was happy to think finally maybe someone understood me a little bit."

Spoon theory speaks to many people with difficult-to-explain chronic illnesses, not only lupus or autoimmune disease. Large enough audiences have read Miserandino's article that calling oneself a "Spoonie" in the company of fellow disabled people doesn't require explanation—if you know, you know. You can buy Spoonie t-shirts and buttons on Etsy. There is no question that the term works as effective shorthand for things that are hard to explain.

As with any concept that catches on in social media and popular culture, there are some strong and valid critiques of spoon theory out there. Most notable are probably concerns about its potential depoliticization of disability. Because Miserandino does not identify racism or structural poverty as daily takers-of-spoons, her model implies that limitations all come from the body itself, not from the outside world.

These criticisms are important, but there are also some elements of the story that have gone relatively unremarked that highlight the political economy of food and what else a disability justice perspective might want to include.

Perhaps most importantly, it's a telling detail that Miserandino and her friend are in a diner when the spoon conversation goes down.

First off, restaurants are notoriously hard physical spaces for people with disabilities. For someone like me, after three hip surgeries, sitting in any one place for more than ten minutes gets uncomfortable, but restaurant chairs tend to be usually hard, narrow, and, in diner booth form, immovable. Because of the neuropathy in my left foot, I usually need to elevate it a few times an hour—not something that's easy to do in most public dining spaces. And that's before we get to menus that don't offer substitutions or that don't list all the ingredients in a dish (a big problem for people with food allergies) or that don't come in Braille.

More to the point, few commentators have examined Miserandino's subtle but unmistakable reference to economic class in "The Spoon Theory." She and her friend are not sitting in a farm-to-table, all organic, GMO-free, produce-forward experimental restaurant, but in a *diner* (read "typical American diner") eating "French fries soaked in gravy." Lest a reader find themselves feeling judgmental about this "choice," it's important to note that a disabled person in the United States would be far more likely to be eating in a similar diner than in a trendy pop-up that follows the dietary tenets of Whole 30 or the Wahls' Protocol. And that's if they could pay to go out to eat a single meal at all. A recent study showed, for instance, that women with disabilities rate their diets as low-quality with little food security (Deierlein et al. 2023).

In other words, our spoons are not just any spoons. They're diner spoons.

Diner food is comfort food for many. It is low-cost, calorie-, fat-, and carb-rich deliciousness and precisely the kind of diet at which eating-for-cure regimens take aim. For a lot of us, diner food is also what is available—in material or metaphoric terms—and what we can afford. To pretend otherwise or, worse yet, to sell people with chronic conditions expensive lecture series, diet protocols, and support groups is a form of willful blindness to the material conditions in which most people with disabilities live. At best, it is elitist and tone deaf. At worst, it is an unforgiveable way to turn people's suffering into profit. Miserandino's story is realistic.

Which brings me to the most overlooked part of her essay: it is actually meant for non-Spoonies. The point of Miserandino's story is not to tell other people with chronic conditions how much time and energy it takes to manage their complex, understudied, and much-maligned illnesses and disabilities. We already know this. The point of her story is the emotional epiphany of her nameless friend, the fact that, by holding spoons and then having them taken away based on the rules of Miserandino's game, she finally became aware that *there was nothing she could do to get more spoons*. Working harder, trying more, just gritting her teeth through it—these were bound to cause her more problems than benefit.

Put another way, though Spoonie has become an insider identification, it's actually a term meant for the spoon-full. Those temporarily able-bodied people who love to say "You know what you should try . . . "

Spoons Full of Morality

Nutrition Hacks: Take Charge of Your Hormonal Health
Take Charge of Your Disease: Living a Long Life through Natural Healing
Cleanse for Healing: Amazing Results to Treat Anxiety, Depression, Acne, Eczema, Lyme, Leaky Gut, Brain Fog, Weight Issues, Migraines, Bloating, and Vertigo Naturally
Healing Foods: Easy Anti-Inflammatory Recipes for a Busy Life
Eating to Cure Disease: Scientifically Proven Diet Changes to Tap the Body's Power to Heal Itself
Anti-Inflammatory Protocols: A Four-Week Plan to Kick-Start Your Immune System and Rebalance the Body

Before you search for any of the titles above, you should know that I made them up. Or, rather, they are fictionalized composites of books and websites many of us encounter every day—in our social media feeds, in line at the grocery store, on talk shows and YouTube channels. It's not news to anyone that huge markets and profits are created by teaching people to be ashamed of their bodyminds. Since Susan Bordo's *Unbearable Weight* (1993), feminists have challenged American culture's obsession with unattainable ideals of feminine beauty and convincingly demonstrated how the circulation of images of "perfect" bodies feeds highly lucrative industries in fashion, exercise, weight loss, and cosmetic surgery, not to mention creating the conditions for epidemics of disordered eating.

Some might say that times have changed. Advertising campaigns do a better job representing a diversity of bodies, in terms of race, size, and age (though, notably, physical disabilities are perhaps the least likely to appear). But as Emma Atherton shows, the focus on thinness as a moral good has been replaced (rebranded?) as attention to fitness or, as it's often known, "wellness." Wellness culture is fatphobia in another guise, without question (2021). But it also draws heavily on ableist notions about disease and healing, particularly a cultural preoccupation with cure in ways that have received very little attention precisely because of the ubiquity of able-ist thinking within "wellness."

It should give us pause that it's now acceptable to talk about people *causing* their own cancer, heart disease, diabetes, or autoimmune condition. Compelling research into mind–body connections are weaponized against those with chronic conditions, particularly women.

These cultural phenomena can be in part traced to certain fundamental understandings of the body in health and illness. Many years ago, sociologist Talcott Parsons wrote about the "sick role" in American culture. When an individual is identified as ill, certain social expectations, especially thosemost connected to productivity and employment, are temporarily suspended. The sick person is afforded certain kinds of attention and indulgence *if* they willingly submit to the authority of a medical expert. This expert will identify the illness and prescribe a course of treatment that the sick person must follow in order to continue to be accorded their special status. If they do, they will be "cured"—that is, return to the presumed state of normalcy from which they began—and then be reintegrated into society as exactly the same person they were before the illness (1951).

To paraphrase the words of Arthur Frank, who studied American illness narratives extensively, every sick person must go on a quest to get better (1995).

Never mind whether questing is an economic, genetic, or physical possibility. If you are not questing for the cure, you are seen as a malingerer.

There's no question that I have fallen for the quest narrative over and over again—the belief that an answer was just around the corner that would give me back the life I imagined I should have had. I've doggedly pursued doctors and diagnoses to try to get to new root causes and treatments.

Sometimes I've had the backing of health insurance, and sometimes it's been an obstacle. Sometimes doctors have supported me, and other times they've ridiculed my ideas. Sometimes I've found something—a medicine, an exercise—that helps, and my quality of life has improved.

Through it all, food as cure was there, beckoning. Maybe that was the golden ticket. But being skeptical of authority of all kinds, not to mention tired and appetite-suppressed, it was a quest route I avoided, a final step I couldn't take.

I was lucky if I got through the day without falling. Pass the cheese, pickles, and cupcakes, please.

Our Hairy Pot and the Deathly Poblanos

And then I started to have allergic reactions to chili peppers. Serious ones, almost overnight. Even a whiff of cayenne in the air could suddenly make me wheeze, not to mention provoke the onset of acute dystonia in the form of tremor and paralysis of the left side of my body. This was very disappointing for someone who considered herself a specialist in South Asian cooking, and it took a few acute episodes for me to actually believe.

For example, in the summer of 2022, my partner and I were preparing for a much-needed summer weekend away from home. I was straightening up the kitchen for the babysitter and went to empty a small compost bucket that we keep on the kitchen counter. As I opened the stainless-steel lid, fine, white filaments that stretched across the charcoal liner and the food scraps inside broke, and in an instant a cloud of gas knocked me back a foot. Presumably coming from the seeds of two poblano peppers I had chopped (but not eaten) the night before, this wave of vapor made me gasp and choke. Immediately, my left arm and leg dropped like a rag doll and my face went into spasm. I slipped to the floor. The babysitter was alarmed. I was able to mouth the word "pepper" to my startled-but-not-totally-surprised partner, who ran out of the room and returned with a bottle of liquid Benadryl.

"Chug," he said.

Feeling my tongue swell in my mouth, I drank a big gulp straight from the bottle, and then another to wash down a handful of other medications we keep at the ready for these emergencies, when I have unexpected storms of dystonia symptoms that are sometimes, but not always, coupled with difficulty breathing, as this one had been. Ten minutes later, the reaction had calmed down some. Thirty minutes later, I was slightly sedated, but the reaction had subsided enough for us to drive away on our trip. The sole evidence of this event was a rash of small red spots in the exact shape of my lungs on both the front and back of my body that lasted for about a week.

The week after the great poblano explosion, I visited my local primary care physician and an integrative medicine doctor. The former wrote a prescription for epi-pens, which we now have stashed everywhere in the house, our cars, work, and my purse. The latter said, "You know, Megan, it's really time to talk about Mast Cell Activation Syndrome and a low-histamine diet." She and I both knew of the documented link between hEDS and MCAS, though neither of us considered ourselves experts on the topic. She recommended finding another integrative medicine doctor who specializes in MCAS, but in the meantime put me on a general MCAS protocol. Opening up the document, I felt a sinking weight in my stomach and hot tears in the corners of my eyes. I had always known that someday it would come to this: I was going to have to follow a restricted diet. Damn.

An MCAS protocol will vary from practitioner to practitioner but essentially consists of (1) taking at least one antihistamine of both antihistamine types at least twice daily (Type 1 includes meds like Benadryl but also newer daily allergy meds like Allegra and Zyrtec; Type 2 targets the digestive system and includes Pepcid AC, Prilosec, and others); (2) taking supportive herbs and supplements; and (3) eating a low-histamine diet. About the diet, my doctor warned me, "It's a doozy. It's not easy. And there's lots of conflicting "data" out there, so you kind of have to find someone you trust and just experiment with what they suggest. Some things will work and others won't. Only you will know."

Quest, indeed.

She recommended the website MastCell360 as a good place to start learning about mast cell activation more generally, and low-histamine diets more specifically.[7] So I went home and started a three-ring binder to collect low-histamine recipes and food lists.

Let me just be real about a low-histamine diet for a minute: it sucks.

And anyone who knows anything about food allergy and specialized diets knows it. A woman who lives down the street from me is a nutritional consultant. When I told her I'd had to go low-histamine, she said, "Oh, I'm so sorry. That one is the worst."

Here's why: rather than cutting out classes of food like dairy or gluten, a low-histamine diet requires assessing every single food you eat on its own for how it does or does not induce a histamine response. Surprising foods are high histamine: avocados, oats, and, of course, all nightshades (which includes tomatoes, peppers of all sorts, eggplants, and potatoes). Others are surprisingly just fine: butter and meat from pasture-raised cows, milk (if one doesn't have lactose intolerance), and corn (in some cases, if it works for you). You can eat fruit, but it depends on which fruit (yes to apples, no to blueberries); you can eat grains, but not even all the whole grains.

But then there's an added complication, which is in the preparation. As soon as food is cooked, it starts producing enzymes that can induce a histamine response in the body; the longer ago it was cooked, the more those enzymes are present. So, leftovers are totally off limits. Imagine, no leftovers! On a real low-histamine diet, you must buy your food as close to fresh as you can, and if you want to prepare foods ahead of time they must be frozen rather than refrigerated. When I began visiting the booth of a local butcher at the farmers' market and mentioned I was on a low-histamine diet, she said, "Oh, then you should come to the Wednesday markets, not the Saturday ones. We slaughter on Tuesday and things go right in the deep freeze. So my histamine people always buy on Wednesday." I thanked her for the suggestion and gaped in disbelief that there were enough of us "histamine people" out there that we could have formed a club.

Not Happily Ever After

Following the low histamine protocol made a difference within twenty-four hours. It was only when the sensation stopped that I realized my mouth and gums had been burning for years. For a non-Spoonie, this would probably be something to pay attention to. In my case, I thought, "Well, everyone in norCal has allergies" and went about my business. Burning gums were the least of my worries most of the time.

The irony is that it was only as I was better able to manage my chronic pain and neuromuscular disorder with traditional medication—I now take a Parkinson's drug that is very effective, a treatment I researched and requested on my own—the role that food sensitivities and allergies were playing in my overall condition became more obvious. It's possible that some of the pain medications were acting as inadvertent mast cell stabilizers. As my need for pain medication reduced, my allergic reactions grew more severe. But it's also possible that my worsening allergies are just due to aging—MCAS seems to get worse over time.

Whatever the reason, the new food changes help. They are onerous and oh-so-bland, but my gums rarely burn anymore, I don't feel like I'm choking all the time, and in combination with other treatments, I am as close to remissions as I've been in more than a decade. The low histamine diet has made a difference.

But I am not an evangelist for this or any other food for cure. I don't even recommend the protocol I follow to others, for many reasons. First of all, living in the hEDS alphabet soup, there's no telling whether diet changes that are taxing and time consuming are worth the benefit. More to the point, how would I know which ones? I could have followed every eat-yourself-healthy program out there and still wouldn't have made a dent in my food allergies because most rely heavily on high-histamine-producing foods like avocadoes and berries. And I would have gone along munching three-day-old leftovers. The low histamine diet is incredibly specific and unlike your typical reduction or FOMAP diet.

Second, I know that for many years the effort that this protocol requires would have been impossible. I lived at an eight out of ten on the pain scale; my son was in elementary school. Every day was a white-knuckle gauntlet of work, family, health, and there were simply no spoons left over. Ever.

The final reason I won't recommend low histamine eating is the most obvious: if you're looking for cure, this isn't it. I am not cured. There is no cure for hEDS; it is a form of the human body, a genetic glitch in the blueprint of my cells. Its impact can be mitigated, the related symptoms treated so that I suffer less and do more of the things I enjoy, but there is no cure.

The evidence that fresh foods, with minimal processing and minimal pesticide and hormone exposure are better for everyone is undeniable. The best thing non-Spoonies can do for Spoonies in the world of diet and nutrition is to help create access to fresh foods—which includes preparation. It's not enough to drop off bags of groceries if a person's arthritis keeps them from chopping or to open a mobile farmers' market if their ability to leave the apartment is limited by post-traumatic stress disorder.

Because people with disabilities are more likely than non-disabled people to be receiving public assistance like food stamps, it may better serve disability justice to work to improve health safety net and food security programs than to send Spoonie friends the latest book on intermittent fasting. This might mean getting involved with local anti-racist organizations addressing food deserts and urban mobility or projects for the unhoused—like the Homeless Garden Project here where I live, in Santa Cruz, California. An intersectional view is essential, one that does not assume that the geography of food and survival can be mapped by outsiders who may miss local forms of agency, but that also takes seriously food apartheid (Reese 2019).

Another thing to be aware of is that asking about diet restrictions, while useful, is not the same as what disability activist Mia Mingus calls "access intimacy."[8] If you care about someone with disabling chronic illness, you'll spend the time to listen carefully enough to their needs that you may be able to start to anticipate them without them having to (re)tell you repeatedly.

And, to my fellow-Spoonies, if you've read this far: You're doing just fine. Try a new food protocol or don't. I will love you either way.

NOTES

1. Following common usage in disability studies, I use the conjoined term "bodymind" to signal, if still somewhat awkwardly, a model of experience and activity that does not rely on the conventional distinction between embodied and mental/psychological/emotional process. I borrow the term from Margaret Price, who describes her view of the bodymind as one in which "mental and physical processes not only affect each other but also give rise to each other," in which they "tend to act as one" (Price 2015).

2. I want to recognize that my experience is not the same as a disordered relationship to food, and this is an important difference. One risk of talking about food at all in the US is that it is almost impossible not to engage in able-ist normalizing about the "right" way to eat, something I'm hoping this essay will work against. So it seems important to mention that eating disorders are complex forms of bodymind difference that exist across a wide swathe of the population, though that is not the topic I'm addressing here.

3. Many food scholars, feminists, and fat activists have written at length about the way that food and body shape are erroneously tied to judgments about character in the United States (see, for instance, Biltekoff 2013). I am also indebted to my colleague, Amy Vidali, for her groundbreaking work on the intersection of disability and food justice; our conversations have deeply shaped my thinking here (Vidali 2022).

4. The website of The Ehlers-Danlos Foundation provides information on the thirteen types, their diagnostic criteria, and their lived effects. See www.ehlers-danlos.com/eds-types.

5. I take this language—"form of the human body"—from a 2017–2018 blog post written by Dr. Chopra on the website of the Center for Complex Conditions of Rhode Island. See https://painri.com/ehlers-danlos-syndrome.

6. The full text of "The Spoon Theory" is available at: https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory

7. The website is here and I think it is clear and well-formatted, though, as this article should make clear, this is by no means a personal endorsement for this or any dietary system: https://mastcell360.com

8. Mia Mingus, https://leavingevidence.wordpress.com/2011/05/05/access-intimacy-the-missing-link.

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