Bodies in Protest

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Explaining Strange Bodies

Something so “practical” as a bodily ailment may be a “symbolic” act on the part of the body which, in this materialization, dances a corresponding state of mind.

(Burke 1989, 80)

A turning point for many of the chemically reactive is the failure of prevailing medical theory and practice to acknowledge their immediate and tangible somatic experiences. It is worth recalling a point made briefly in the last chapter. By the time the chemically reactive are seeking the counsel and care of physicians, many of them have already developed a rudimentary understanding of their troubles. Matching variable environments and consumer products with variable symptoms, people approaching the medical profession know something useful about their somatic complaints based on immediate, tangible experiences.

It is this practical, useful knowledge that is generally unacknowledged by physicians. A physician might listen respectfully to the accounts of a patient who has catalogued an extensive array of associations between his body and local environments but is not likely to
be able to explain these untoward occurrences. In the absence of a professional account of their taxonomic work, the chemically reactive are encouraged to deny the sovereignty of their senses. It would matter little to them to know their situated experiences affirm the modernist assumption that personal experiences must be secondary to professional judgment (Beck 1995; Touraine 1995); to abide by this assumption, however, is to risk their immediate health and well-being.

Between the self of the chemically reactive and the authority of medicine is a recalcitrant, protesting body. Physicians, of course, can attempt to legislate this body, defining it in a manner that allows them to explain it—perhaps telling the patient he suffers from an unusual type of allergy or a neurosis. Or they can reject this body, dedicating themselves to bodies amenable to conventional medical practice. The self in the chemically reactive body, however, cannot, like the peripatetic crab, move out and shop around for a safer home. Unable to emancipate the self from a recalcitrant body, the only other option is to emancipate the self from the authority of the physician. But the act of turning away from a physician will not by itself produce an understanding of why the body is changing.

Like all of us, the environmentally ill are chained to the wheel of meaning, bound by a species need to make sense of their lives. Once associations are made at the immediate moment of the body’s response to environments, the self must understand its experiences of a changing body. Perhaps the old saw that “what we don’t know can’t hurt us” is true some of the time, but for the chemically reactive, knowing can prevent them from being hurt.

The narrative materials in this chapter reveal two interrelated processes: the disenchantment of the chemically reactive with physicians, an often painful process that results in separating biomedical language from the medical profession, and the cognitive work of the environmentally sick to transform their illness experiences into a disease theory using a borrowed medical vernacular.
The Chemically Reactive and the Physician

In this section we will examine why those with MCS are likely to move away from the personification of the medical model, the physician, and toward its most abstract expression: biomedical language. A former nuclear engineer severely disabled by MCS recalls:

I went to three neurologists, two cardiologists, one rheumatologist, two internists, two hospital clinics for full evaluation including the Mayo Clinic. Also I had been analyzed by two psychologists, one psychiatrist—tested for depression, mental disorders, also medical procedures like MRI, EEG, ultrasound, X-rays repeatedly, and hospitalized three times.

She then summarizes the variety of medical attempts to diagnose her troubles, recalling one physician who admitted her “disease cannot be treated.” The rest, however, offered more concrete, if cautious, opinions.

May be temporal arteritis, may be fibromyalgia, may be conversion reaction disorder, may be scleroderma... The “May be’s” kept going on—only a few facts remain the same which all the doctors could not ignore: I am losing my teeth very fast, losing my eyesight, and my eyes are bleeding... And I have severe headaches and hearing loss.

Finally, she makes a plausible argument for the somatic basis of her illness:

I am not a hysterical person or psycho or faking my symptoms—I was a professional making more than five thousand dollars a month. Now I am living off Social Security disability of nine hundred dollars a month, or 20 percent of my original income... I would have to be stupid or demented to accept that cut in income or status.

For this woman and most of the other chemically reactive people we interviewed, there are few, if any, perceived secondary gains associated with EI.
A graduate student writes regarding her experiences with physicians:

My overall experience with the medical profession has been varied. I have had the very good fortune to have had several excellent physicians in whom I was able to place my trust. The first, when I lived in New York state, was an internist with many subspecialties, on the faculty of a medical school, and chief of staff of a hospital. Years later, about two and a half years after the crop-dusting incident, when I was still not recovering very well and doctors in this western state did not know what to do with me, I went back to New York to have this internist examine me. After an exhaustive workup (ten days in the hospital) he told me that I had allergies and sensitivities, but he didn’t know of an allergist who could adequately treat them in my part of the country, so he put me on Benadryl and sent me home. Three months after returning home I became allergic to the Benadryl and started going downhill rapidly. At one point I was hospitalized (it was during this hospitalization that my first husband left me) and I was told by a local physician at the hospital, “If you don’t straighten up, you will die.” He never did explain what he meant by “straighten up.” I was losing weight rapidly and in a great deal of pain.

In this passage we hear about physicians who are not abandoned by the chemically reactive and do not abandon them, who are resisting the lessons of medical school and the conclusions of medical societies to accept the possibility of a new, incongruous body. When this happens we witness a curious moment: the layperson stepping out of the expert.¹ We will have occasion to say more about maverick experts who step away from their professions and toward citizen movements in the final chapter.

Combining references to philosophy with genuine anger, a former attorney lashes out at the medical profession while acknowledging the importance of physicians who are willing to listen and learn from patients:
Almost invariably, among those who do not specialize in MCS, experiences are very negative—ranging from outright denigration to covert skepticism. Once again, one tries not to see this as personal rejection, but against a sociopolitical-historical background the Cartesian paradigm, science’s insistence on visible proof rather than empirical observation, etc. The negativity of the mainstream medical profession, however, is countered by the few dedicated, wonderfully humane doctors we’ve met who are working in the MCS field—here, they are often persecuted for practicing such heresy, so their stance and support count for much. Once again, an understanding of the pathways of MCS initiation and response provides a good coping mechanism in the face of medical hostility and skepticism. After several abortive tries to find a suitable local physician . . . I found my current local physician, a family practitioner, who, although not terribly knowledgeable about MCS, treats me with respect and as a credible patient, and believes that I have MCS. This physician graciously accepts literature on MCS when I come across it and usually asks me what I can tolerate when I need medication, which does happen occasionally. How refreshing it is to be treated as an intelligent, rational human being with some knowledge of what is good for me and what is not good for me!

A professor of English literature who is on a disability leave recognizes the difficulty physicians face when they encounter the body of the multiply chemically sensitive:

A Social Security psychiatrist diagnosed me as “Schizophrenic, hypochondriacal type.” The medical profession has been caring and responsive, doing the best they can with a new and unusual illness or disease that does not fit their models. Their skepticism is understandable—for example, when I tell my urologist my prostate inflammation is caused by breathing wood smoke in the winter, he thinks he’s speaking with a fool, because there is no training at med school to suggest inflammation comes from environmental exposure.
A legal secretary is less sympathetic with her doctors. She describes herself as:

very angry about the fact that several doctors I have seen failed to even question that my illness could have been something other than bronchitis, sinusitis, or asthma. Over a period of nine years I saw the same clinic of allergists (three doctors) and not one of them ever suggested anything other than allergy injections, nasal and bronchial inhalers, cortisone, and antibiotics in response to my continued deterioration of health. Even after I explained my extreme reactions to perfume, no one ever suggested that it might be MCS/EI, including the pulmonary specialist and ENT.

Evident in her story and those recounted earlier is the routine failure of physicians to normalize their patients’ somatic distress. Whether it is called temporal arteritis, fibromyalgia, allergy, a neurotic-somatizing disorder, or one of hundreds of other standard medical diagnoses, from the vantage point of the chemically reactive, the definition does not match the misery, nor obviously does it cure it.

A professional writer offers a somewhat unflattering explanation for why physicians persist in trying to fit MCS into something they know rather than expand what they are prepared to know:

I have found that most physicians lack intellectual curiosity, and when faced with a patient who doesn’t conveniently fit into their medical mold, they prefer to discard the patient into their medical wastebasket, rather than revise their medical paradigm. With only a very few, notable exceptions, conventional medicine has been a huge disappointment for me. Most of these practitioners have an ego that gets in the way of listening to the patient and a strong, strident bias against anecdotal evidence.

An orchestra conductor summarizes how many people with MCS feel about the medical profession:

My experiences with the medical profession have been appalling—even horrifying. These people are generally callous, abusive, self-important,
insecure persons who care far more about their cultish allegiance to 1940s medical texts, and the reputation they believe they will maintain thereby, than to human life or any oath to protect it. Most are, at best, smugly complacent.

Finally, consider the words of a man with severe MCS and no medical insurance:

As I was too poor, with no medical insurance, to go to many doctors, I haven’t had to deal with them. The two doctors I did see in six years told me that they didn’t know how to treat me. I went to the emergency room at a Little Rock, Arkansas, hospital once after passing out from a chemical overload. The attending physician thought I was “crazy”; I thought him an “old fool.”

Worlds collide in these accounts. The physical, painful, mysterious body of the chemically reactive crashes against the orthodox knowledge and practice of a powerful profession. Unable to take a proper measure of this body, to fit it into what physicians know about bodies, it becomes an unwelcome anomaly. What is a concrete and disabling disorder for the chemically reactive is, simply, medically impossible for the physician; thus the patient is “crazy” and the doctor a “fool.” A woman with severe EI concludes her account of experiences with the medical profession with the following counsel: “I formulated the only two rules for MCS that always hold true in all circumstances: 1. Nobody knows anything. 2. Nothing makes sense.”

Between the lines of the several accounts just presented are two contradictory orders of knowledge: a personal and visceral way of knowing and an authoritative claim that one cannot talk reasonably in these terms. “The biomedical model,” writes a professor of medicine and psychiatry, “embraces . . . reductionism, the philosophic view that complex phenomena are ultimately derived from a single primary principle.” In this case the nonexperiential, purely “physicalistic . . . language of chemistry and physics will ultimately suffice to explain biological phenomena” (Engle 1977, 90).

A key to understanding modernity is the authority of expertise to
disempower the senses (Beck 1995; Touraine 1995). From physics, to biology, to sociology, we are taught that the world is not what it appears to be; we should not trust what we know, or feel, or see. A physician warns his medical colleagues who might be tempted toward acknowledging the validity of a patient’s personal story about his body:

To allow more than objects to enter our experience [as doctors]—really enter—would entail a painful reassessment of who we are. It would mandate a redefinition of our relationship to the world, a renunciation of the ordinary subject-object way we habitually define ourselves. (Dossey 1984, 5)

The promise of modernity captured in this physician’s warning to his colleagues is easily discerned: surrender the sovereignty of your senses to the authority of administrative expertise, and in return you will enjoy the benefits of legitimate and reliable knowledge about your body, your self, and the world you inhabit.

A woman writes as if she is challenging the legitimacy of this promise:

I have to be aware of my environment, and my body’s reaction to it, subjective or objective. (By the way, technically, the environment includes that which we take internally, such as artificial sweeteners, and drugs—anything which is non-self.) This is a part of trusting myself. To ignore this is to risk serious illness for a long time, even death. I try not to be paranoid and don’t think that I usually am paranoid. I only wish I had learned to pay attention to the “wisdom of the body” a lot sooner.

On the body as a source of reliable knowledge, consider the thoughtful, if somewhat prickly, observations of a retired grade school teacher:

I think the diagnosis of MCS is correct because I obviously do not have Candida anymore according to a stool analysis done last year, I am not chronically fatigued anymore, and, with proper testing in an environ-
mental unit, I am sure many of my reactions could be replicated in a single-blind manner the same way they are repeated when I get exposed to whatever is causing them. I trust my body, not my MD. . . . I think my common sense has always been there although the medical profession and circumstances did their best to obliterate it. I feel more strongly about it now than at any other time in my life. Now, it’s here to stay.

The credibility of modern medicine, for this woman at least, is a matter of institutional commitments and not of explanatory coherence. Refractory bodies cannot be ignored. They intrude into consciousness and demand to be explained. It is an unusual person who can adapt to a disabled body in the absence of a reasonable account of how and why she became sick. The chemically reactive people we interviewed are anything but unusual, at least on this one measure. Without the benefit of a standard medical diagnosis, they have fashioned their own medical realities, borrowing liberally from the grammar of biomedicine. Forced to become students of their recalcitrant bodies, they continue to monitor their somatic reactions and search relevant literatures, particularly the research literature on MCS.

**Constructing a Practical Epistemology**

A woman who has lived with the illness for over twenty years recalls her first efforts to know what was happening to her body: “I started studying, reading everything I could get my hands on. I have quite an extensive library but there’s so much coming out that I’m getting behind. I have books, newsletters, tapes.”

“After no help from a poorly trained MD,” writes one man, “I started reading and making phone calls. . . . you just have to take control of your medical needs.” A bookkeeper notes, “I read everything I can find and doctor myself.” A woman with MCS encourages fellow sufferers to “be your own private detective agency. Look for clues everywhere. . . . You can never know too much about this stuff” (Lawson 1993, 318). Another woman acknowledges the relationship
of knowledge to personal empowerment: “I avidly go after any information I can find on MCS and related issues. I’ve become a source others recommend for information; and a fine investigative journalist I know says I ought to be an investigative journalist.”

A young woman with severe MCS describes the process by which she has created her own library:

I first learned about MCS by reading a letter to an editor in my local newspaper (at the time I was living in Baton Rouge, Louisiana). It was the first time that I had ever read anything that so closely described my personal experience. It was virtually biographical! I contacted the organization that had sponsored the letter (HEAL of Louisiana). . . . It was Diane who opened her heart and her personal library to me. I try to return this gift, every day, when I receive calls from “novice” EIs. I remember starting a single file folder headed “EI/MCS.” Now I have two rooms (home offices) full of file cabinets and bookshelves. My husband teases that we will soon have to build an addition to our house, to warehouse all my books, files, videos, etc.

In a more restrained admission of the importance of literature on making sense of somatic experiences, one man writes:

Well, I read about MCS in newspaper articles and books as I tried to figure out why I was ill. I read about multiple chemical sensitivities in relationship to cleaning up one’s environment and realized the symptoms were the same as those for chronic fatigue syndrome. Then I began to notice how symptoms intensified after driving in car fumes, being exposed to a new building.

For this man, literature and secondary associations became a substitute for physicians’ counsel.

I first learned about MCS from an article given to me by a previous roommate. After that, I contacted the Environmental Health Network and did research on my own to learn more about the illness. I then determined that I was chemically sensitive even though I had not been diagnosed at that time by a physician because I lacked insurance.
A middle-age man links his natural curiosity to his search to find out about his disease, justifying his work by acknowledging that, like other living creatures, he too can be poisoned:

I don’t remember how I first learned about MCS. I am a very curious person, always investigating and learning. My first indication was from the doctor who identified the phenol poisoning. That gave me a starting point and then magazines like Sierra Club, Greenpeace, and CMC publications. After all, I am an animal, too, and can be hurt just like other fauna.

A woman explains why knowledge is a practical necessity: “I learn all I can because I intend to be well.” Echoing her intent to learn, another chemically reactive person writes, “I’ve become a student of my body and of this illness. I read extensively in order to understand MCS and how best to treat it.” “Once you find the cause,” one man writes, simply, “you have the cure.” His optimism, however, is not shared by everyone. A beautician notes, “The last two years I have read everything I can find about MCS to cope with this problem. . . . What is a puzzle to me is I have tried to build my system up to overcome this problem and it just doesn’t work.” Becoming students of their bodies’ disorders did not in fact result in cures for any of the respondents, but each recognized the importance of learning to successfully cope with their troubles. A retired real estate manager acknowledges the importance of learning about bodies and environments to adapting: “I have done a lot of research on my own and have found some things that help me deal with this horrible illness.”

While other respondents wrote longer accounts than those presented here and some wrote shorter ones, the pattern of ordinary people engaged in constructing a way of knowing that is adequate to comprehend the untoward changes in their bodies is evident in all of the interviews. In the talk of the chemically reactive we see the work involved in fashioning a knowledge about bodies in the absence of medical recognition that real, somatic problems exist.

A common theme in these narratives is the sense of responsibility
the chemically reactive assume for knowing the body and its relationship to environments. Their survival is directly linked to the knowledge they produce through systematic observation of their bodies, accompanied by medical and technical reports and conversations with others. To survive MCS, they believe they must know more than the medical professions and most physicians about somatic responses to specific environments. If the boundary between expert and layperson is wearing thin, it is because ordinary people are increasingly forced to theorize their mundane miseries, often in the face of hostile or doubting experts. As we will see in the final chapter, knowing more than the expert whose job it is to know is an increasingly common survival strategy in a society fashioned by a growing number of seemingly unmanageable risks.

Accounting for how and why the chemically reactive learn, however, is only one part of the story. A second, and critical, part is what they learn. Under considerable pressure to supply precise understandings of their refractory bodies, the chemically reactive must satisfy not only themselves but others of the legitimacy of their disorder.

Explaining Bodies and Environments

The following passages narrate the work of people who need to conceptualize their troubled bodies. Here abstractions meet somatic complaints, and together they constitute a new, practical epistemology: a sensible, local, and instrumental way of knowing bodies and environments. The clusters of words used by the chemically reactive to explain their bodies are, more often than not, borrowed liberally from the vernacular of biomedicine. A former computer programmer believes he “must sound like a doctor to convince other people and myself, I guess, that all this crap I go through is real, natural, not just mental.”

Fashioning biomedical accounts of the etiology and pathophysiology of their disorders allows the chemically reactive to know what they are experiencing and in turn informs their experiences of the dis-
order. In their work to understand their misery, the chemically reactive are blurring the conventional boundaries between illness and disease, a topic we will return to at the end of this chapter. For the moment, however, it is enough to comment on some properties of the narratives themselves.

First, note the diversity of biomedical accounts of MCS. Indeed, some people ascribe to an entirely different name for the disorder. The lack of a common, agreed upon nomenclature for EI adds considerably to the deliberative work of determining just what is wrong and why. Multiple chemical sensitivity remains a local, individual, or, at most, a small-group problem. While resources are available at regional and national levels in the form of newsletters, tapes, books, and so on, there is little common ground for reaching a shared definition of the disorder. At this point in its development, an explanation of MCS is truly a local knowledge. In spite of their parochial character, however, most definitions do share a common feature.

Regardless of the variable clusters of words chosen by those with MCS to represent their sick bodies, the theories of chemical reactivity constructed in these accounts almost invariably link the body to the external environment. For the environmentally ill, environments can no longer be understood as outside the body. Healing a sick body begins with a working knowledge of the physical and chemical settings to which it is inextricably linked. Most of us conceive of a boundary between our bodies and external environments. We are accustomed to thinking along such lines as “This is where I stop and nature, wilderness, the neighborhood, and so on begins.” For the chemically reactive, however, knowing a body is inseparable from knowing the chemistry immediately surrounding it. The following five narratives illustrate both the diversity of lay disease theories and the often technical language used to explain them.

An inventor and sales representative explains his disorder in the highly stylized language of immune system medicine. Realizing he might be confusing a sociologist, he moves from a more difficult to an easier explanation of his troubles:
I personally do not like the term MCS or EI or chemical hypersensitivity. I like the term toxic response symptom. I like an inappropriate inflammatory affected lymphocyte profile, but we must communicate. The easiest description is that the chemicals have developed a binding site on proteins that arouse the immune system to produce too many helper cells that proliferate throughout the body and interfere with my body’s ability to expel the unwanted chemicals. I lack adequate detox enzymes to protect me from these toxic chemicals so they cause damage to cells and autoimmune system.

A graduate student believes her troubles are caused by problems with her vascular system. “Countless exposures to supposedly safe chemicals over twenty-eight years are causing my blood vessels to become weakened and inflamed. Parts of my body are no longer getting an adequate supply of blood. I believe this is the source of my chronic pain.”

A massage therapist directs attention to the importance of the limbic system in explaining MCS:

In my opinion, the theory with the most merit . . . in explaining the symptoms, according to the results of research, is that the limbic system of the brain has been damaged by chemical exposure. The limbic system, also known as the “animal brain,” controls basic bodily processes, regulates both the endocrine and the immune systems, contains the “search function” for our memories, and influences our emotions. Inhaled chemicals are known to migrate directly to the brain via the olfactory (smell) nerves. The sensitized limbic system reacts abnormally to these exposures. This has been documented through sophisticated technology such as the SPECT scan. This abnormal brain response then impacts the rest of the body, resulting in the many diverse symptoms of MCS.

A man who lives on a boat off the Maryland shore narrates his version of MCS:

I don’t have the ability to be exposed to certain families of toxic chemicals. . . . the toxic chemicals accumulate and store in my fatty tissue.
This then activates my immune system and causes autoimmunity and an inappropriate inflammatory process that then lacks the immune component that turns off the activation. Any organ or tissue can be the target of immune attack. After enough attacks, the organ or tissue dies.

A retired navy officer explains MCS as resulting from “a deficiency in the enzymes in my body that are supposed to neutralize toxic chemical substances that I encounter in my day-to-day activities. . . . Enzymes are proteins that work to clean up the body. Mine are not working.”

In each of these accounts, the source of MCS is located outside the body—for example, in “certain families of toxic chemicals.” Theorizing relationships between modern material culture and sick bodies often occurs in tandem with a language of moral accountability. Fusing technical and medical talk with the rhetoric of social or environmental justice ensures that EI, however it is defined, is both a disease theory and a form of social criticism. In this way MCS is not only a collective representation of problems with bodies and environments; it is also a representation of imperfections in the body politic.

A middle-aged man who works as a substitute teacher and sells automobile insurance explains his disorder using a mix of cellular, evolutionary, and moral appeals:

MCS is a central nervous system response to dangers that we are not consciously aware of. At some point, the central nervous system senses a chemical danger that could in high enough doses cause an injury or disease. . . . Since the first single-cell organism, organisms have been responding to low concentrations of chemicals. . . . Humans have a more complex reaction to poisons than many other species. . . . We delegate portions of our populations to work with chemicals so others can have leisure. We tolerate poisons to make our homes or selves look better. . . . In an effort to save the organism, the sensing organ ups the volume of its output. The nose or skin . . . senses chemical concentrations and tries to say to the body, “Get out of here. You are in danger.” If the body doesn’t listen, the sending sensory nerve cells up their output volume until the body can hear.
An unemployed legal secretary and office manager understands her disorder as involving immune, limbic, and olfactory systems. She finds it particularly difficult to live with because it is “invisible” to others and renders the body unpredictable.

Chemical sensitivity is an illness where a person has severe reactions to low levels of chemicals which are used in almost everything we use in our lives, to prescription drugs, and to foods. A person becomes chemically sensitive by either a long-term overexposure to low levels of chemicals, including, but not limited to, new carpets and other building materials, chemical spills, pesticides, etc. Manifestations of MCS may include body swelling, rashes, violent convulsive coughing, chronic fatigue, severe muscle aching, problems focusing eyes, short-term memory loss and inability to concentrate, stomach and other organ problems, and numerous other symptoms. Usually a person with MCS manifests many of these symptoms all at once and they become very depressed. Their bodies have become so toxic that their immune systems have been damaged to the point that they are literally unable to tolerate even traces of chemicals in products they have used all their lives and which others use with no reaction. Chemicals undetectable by the olfactory senses cause them to experience acute symptoms which frequently leave them too weak to function. MCS patients have different levels of damage. Some require oxygen to go outside. Some must wear masks at all times because they can’t take the chance of being exposed to anything that will cause them to react. Many cannot even tolerate their own living environment. Sometimes, MCS patients’ immune systems are so weakened that they must use a wheelchair or walker to get around. Many chemically sensitive individuals look perfectly normal, not sick at all. MCS is an invisible disability, and because of that many people don’t believe it exists. This lack of belief by others and the fact that MCS patients cannot trust their bodies any more not to betray them in public are very difficult to deal with.

A retired professional woman starts her account by building a technical case for her troubles, but she ends on a note of earnest appeal:
The condition is basically one of immune system dysfunction (sometimes called autoimmune disease), but it is not AIDS. The body becomes hypersensitive to a multitude of external and even internal triggers (such as mold, dust, pollen, gases, chemical fumes, even its own hormones). This hypersensitivity produces a host of severe symptoms in a variety of organ systems of the body including debilitating fatigue and muscle weakness, migraine headaches, depression, edema, skin rashes, and inability to concentrate. The body may even attack its own cells and tissues. It is a frustrating and sometimes depressing illness, and while I try to remain optimistic and upbeat, I could use your help, support, encouragement, and understanding.

A professional writer explains MCS as a “chemical injury”:

Only a small percentage of the population exhibit what we’ve come to accept as “allergies.” This is really an altered state of reactivity to some benign environmental substance (e.g., pollen). MCS is a diagnosis that refers to “chemical injury” on exposure to substances that have a potential for harm to everyone, when presented in a large enough dose. For example, there is no safe level of exposure for formaldehyde. Pesticides contain known neurotoxic agents. My heightened reactivity is in response not to pollens but to synthetic chemicals that are recognized within the scientific community as requiring “threshold limit values” and “permissible exposure limits.” Their “risk assessments,” however, protect only a portion of society. They haven’t safeguarded my health.

A disabled orchestra conductor explains her disorder as if she is talking to others, suggesting the importance of a disease theory in constructing a legitimate social identity:

I think MCS is the correct diagnosis, given the current usage of the term; but I don’t believe “MCS” is a diagnosis at all, in that it is merely descriptive. I understand that “MCS” was coined by an MD who was antagonistic to the recognition of the disease. My objection is that it says nothing of the mechanism, or what it is. I prefer “RUDS (reactive
upper airways disease) with toxic encephalopathy.” To a nonscientific friend, I will simply say I’m “chemically sensitive” or “chemically reactive.” At times, with certain people, I have no objection to their understanding that I am “allergic to chemicals.” In the common usage of “allergy,” this is not terribly inaccurate. I am, however, very quick to correct mistaken MDs, and those who try to trap me: “Oh, so you feel you’re allergic to chemicals?” they say with that condescending tone. I snap back, “Not IgE,” and go on to present a plausible biomedical model, which invariably causes their eyes to glaze over.

As the preceding narrative suggests, distinguishing MCS from allergies is important to many people who are theorizing their bodies’ intolerance to chemicals and environments. Biomedical accounts of normal allergies locate the source of the disorder in the body, specifically in hypersensitive IgE antibodies that mistake ordinary environmental agents, pollen, dust, and so on, as toxic. For the chemically reactive, however, the problem does not originate in their bodies but in chemically saturated environments. The distinction is important for many reasons, not the least of which is its mandate to expand the medical gaze beyond the body to include houses, stores, streets, parks, offices, and libraries, among hundreds of other places, as possible sources of disease.

Note how language is used in the following accounts to distinguish MCS from allergies. A retired computer program analyst explains:

The term allergy generally refers to a genetic disorder that involves acute . . . reactions mediated by an antibody called immunoglobulin E. I don’t have this. My problem is an acquired one that comes from toxic overexposure and produces delayed reactions which can come in response to very tiny amounts of airborne contaminants, . . . food additives, and some foods (the list of which is always changing).

A phone consultant describes environments and chemicals filling bodies, an etiology story far different from that of IgE-mediated allergies.
MCS is an accurate diagnosis of my illness because I react to all chemical substances in a negative way. It’s not an allergy. As I go through my daily routine I am exposed to various chemicals. Once I reach my total body load, I have a reaction. Some days it may take longer depending on exposures and this confuses people, as they may see that I have briefly visited a mall. However, my symptoms can be turned on and off like a light switch. Expose me to a chemical, and I will have a reaction. Spray the room with bug spray and when I enter my vision will dim or I will become aggressive or feel strange, without even knowing it has been sprayed. The reaction depends on what I have been exposed to prior to that exposure. Not all reactions are the same and this confuses people. Take me away from all man-made materials and chemicals, including our outside environment, and I will feel mostly normal as long as I don’t read or clean the house or do anything that might result in a reaction. However, prolonged exposure to my own home causes fatigue and brain fog. I must change environments at least twice a day to detox.

A farmer contextualizes MCS by locating its origin outside the body, accuses an allergist of causing a toxic reaction, and suggests the disorder is reaching pandemic proportions.

I think MCS is an accurate diagnosis because my illness was precipitated by Agent Orange poisoning and I react to many chemicals, in addition to natural allergens, and my reactions rarely produce antibodies but rather symptoms of poisoning. For example, my digestive tract reacts more like I have eaten arsenic than a common allergen like a banana. My respiratory tract acts like (especially burning) I have inhaled a poison like sulphur rather than a common allergen like pollen. I became allergic to molds only after the allergist poisoned me with phenol in conjunction with a mold allergen. And since when is it normal—or at least natural—for everybody to have allergies? Fifty percent of the population of Chico (or more now) have “allergies.” This may be “normal” but it is not natural. It is artificially induced ill health in an entire population surrounded by farm country and sprayed pub-
lic lands. I also don’t think MCS is an adequate term. I think something like multiple artificially induced sensitivities (MAIS) would be more appropriate. The only “allergies” I had all my life before the Agent Orange poisoning were to milk and poison oak. Now hundreds of substances disable me with MCS while giving other people less obvious reactions—cancer, leukemia, CFIDS, MS, Parkinson’s, etc. Poisoning is epidemic!

A retired accountant uses allergy as a metaphor to explain how MCS is different:

Multiple chemical sensitivity is somewhat akin to an allergy, in that we get sick from things that don’t affect other people. But, in many ways it’s far more serious than getting hay fever from the cat or from pollen. People with MCS react to things that are all around them, everywhere they go: things like plastics and carpets and perfumes. And their reactions can be far more serious than sneezes and spots. Some people might suffer blinding headaches or become paralyzed. Others might become hyperactive or violent. And others might be unable to remember things, or to concentrate enough to learn at school, or to function as members of society. It’s all very individual: everyone has different reactions, which may affect any part of the body, and reacts to different things. This is what makes it so hard for the average doctor to diagnose or understand—and for the unaffected person to accept. This often makes it difficult for the patient, who may find it hard to cope with rejection and disbelief, on top of his illness. Some people are so sensitive, to so many things, that they are forced to live in virtual isolation. While such a situation may seem incredible to the unaffected person, there are many people—all over the Western world—in this situation.

One observation seems rather obvious from these accounts: EI is not a single, coherent practical epistemology. It should perhaps be thought of as a discrete, highly personal resource for talking about bodies, environments, and society. Separating languages of expertise from expert systems and locating them in situated, personal lives
ensures that the chemically reactive are, to paraphrase Geertz (1983, 10), constructing texts ostensibly medical out of local, biographical experiences. Each of the narratives recounted here bears characteristic marks of a unique self. Environmental illness is less a collective representation of bodies and environments and more an invitation to think through the immediate, tangible, and particular relationships between a self, its body, and its chemical surroundings. Its particular rather than universal mode of reasoning makes it infinitely adaptable to the needs of discrete persons and their sick bodies, though it violates a condition of rational knowledge that it must be generalizable.

Interpreting Theories

What are we to make of these highly variable, often moral, accounts of the etiology and pathophysiology of MCS, EI, or one of their corollary terms? The question can be approached from several vantage points. A good place to begin is with the problem of knowledge and the environmentally ill body itself.

A sick body insists on being understood. It is almost as if the disorder of a body requires the order of a text. As in this case, a body experienced as chemically reactive encourages a pattern of thought about environments, immune systems, limbic systems, central nervous systems, and so on. Human sickness reminds us of a somewhat messy proposition, namely, the question of how we know bodies cannot be separated from the question of how bodies know. It is worth a brief foray into the more well-known strategies for addressing the idea that bodies are both objects and subjects, a topic several of our respondents addressed in one way or another.

Foucault (1977) addresses the dual properties of the body by ignoring its agentic possibilities. His body is simply the product of language, a discursive object of control and surveillance. For anthropologist Margaret Lock (1993), the body is more than a state-sponsored language; it is also “an active forum for the expression of dissent and loss” (141). For the teenager who pierces his lips and nose with rings,
the body is a physical location for symbolizing separation from authority and attachment to others who are perhaps also piercing their bodies. The idea of the body as an expression of belonging and dissent is a corrective to Foucault’s exclusively normative body, but both approaches examine a body as an object acted upon by the state or the self. How would the chemically reactive respond to Foucault’s and Lock’s notions of the body as a social construct, an expression of order and dissent?

A retired Navy officer is troubled by “psychiatrists and psychologists who make their living telling us it’s all in our heads. I told a shrink, ‘my head listens to my body.’ He smiled and continued to ask me questions about my anger.” Examine a number of comments culled from the interviews that strike a similar note: “I believe what I experience”; “I know what I feel”; “If I doubt my body I doubt my mind”; and “Throughout the day I listen to what my body is telling me. If I don’t I can find myself in some real pickles.”

Finally, consider these comments made by a primary school teacher: “I trust my body. It’s the only thing that has been predictable throughout this craziness. . . . If I listen to a doctor, many of them anyway, I probably stay sick or get sicker. But if I listen to my body it tells me what to do to survive.”

Contrary to Foucault and others who would see bodies as little more than clusters of authoritative words or physical expressions of dissent, the chemically reactive believe their bodies know things. These quotes express an assumption that bodies possess extradiscursive properties that are important, in some instances, for survival. For those with MCS, perceiving and knowing are not exclusively activities of the self or the state but are shaped in part by the body and its relationships to environments. For them, the body participates in the structure of their imagination; as it changes, becoming less tolerant of modern commodity culture, it encourages them to rethink what they know about their physical selves and the environments surrounding them.

If visceral knowledge is not reducible to culture, however, it is only through culture that such knowledge is represented. And it should
come as no surprise to learn that the organization of modern commodity culture discourages the representation of body knowledge (Martin 1990; Sheets-Johnstone 1992). We are more apt to attend to the messages of popular culture regarding our bodies than to our bodies themselves. Male and female fashion models, nutritionists, pharmacological researchers, physicians, and weight and fitness experts are among the many voices that speak for bodies. For one commentator, “The living sense of ourselves vanishes in the din of popular body noise” (Sheets-Johnstone 1992, 3). The body as commodity overshadows the body as a source of prediscursive wisdom. If the Cartesian revolution reduced appreciably the voice of the body as a source of knowledge, its successful appropriation by market forces rendered it nearly mute.

The environmentally ill body, however, is fashioned, for all practical purposes, without the benefit of institutional representation—indeed, in opposition to it. In a culture where visceral knowledge is expropriated and replaced by languages of advertisers and physicians who know best, crediting the body with its own authoritative voice is likely to be accomplished in a language of opposition and difference. Throughout chapters 3 and 4 we encountered languages of opposition created by the chemically reactive to give voices to their troubled bodies.

The environmentally ill body appears to encourage imaginative work expressed in a language of biomedicine that is opposed both to the medical profession and to the built and modified environments of modern commodity culture. Specifically, EI is a lingual resource for constructing the unsettling idea that commodity culture itself is, in fact, sick—contagiously so. In this fashion MCS becomes clusters of words for representing bodies protesting their troubled relationships with much of the material of modernity.

There is in fact one area where these diverse narratives converge: etiology. A dizzying number of pathophysiological possibilities are embedded in these accounts. Advocates for central nervous, limbic, or immune system disorders vie with advocates for upper airway
obstructions, brain inflammation, and the somewhat general chemical injury, among other accounts of what is sick. This diversity of disease pathway stories, however, is not matched by a diversity of disease origin stories. While there are some biographical differences in the specifics of causality (acute versus chronic, for example), all accounts of EI—including those found in chapter 3—locate its origins in pathogenic or sick environments. As theories of the sources of sick bodies, etiologies are inevitably moral and political accounts. While causality is never really independent of casuistry, the rhetoric of biomedicine would have us believe the origin of disease is almost invariably in an amoral, natural body.

Biomedical language routinely transforms somatic complaints into a powerful rhetoric of naturalism that locates sources and solutions in the chemistry and physiology of the body (Martin 1987; Kozak 1994). Physicians and medical researchers routinely use biomedical language to depoliticize diseases by locating their origins in the body (Sontag 1989; Lock 1993). For their part, physicians do not intentionally obscure the social, political, or environmental origins of disease. Rather, they routinely treat bodily symptoms, seeking, as their licenses proscribe, to treat the sick body. The net result of this approach, however, is the idea of the body as the origin and site of disease. From this vantage point, the body is indifferent to moral appeal; it is neither good nor bad, just sick. One can blame the person for getting sick, of course, but that is beside the point in the clinical encounter, where the emphasis is on a cure.

In spite of the fact that modern medicine denies the value of certain kinds of relationships—putatively benign environments and disease, for example—those relationships remain linguistically available to individuals as a basis for generating an alternative way of understanding what makes bodies sick. The practical necessarily becomes political as the chemically reactive argue for the origin of disease outside of their bodies, specifically in putatively benign built and modified environments. Their narrative accounts contain an alternative strategy for the origin, development, and deployment of medical knowledge.
Finally, with a few exceptions, the patterns of thinking recounted in the narratives presented in this chapter include an extrarational, often emotional, moral appeal. Two orders of persuasion—the technical and the moral—are joined here into one account (see Chapter 2). While a moral appeal typically enjoys more credibility than one grounded in an alleged physical reality, combining the two expands considerably the number of venues a person can hope to influence (Epstein 1991, 1995). Perhaps the practical epistemology of EI heralds a new strategy for citizen action.

Most social movements share a populist appeal to rights and entitlements based upon the idea of citizenship (Waltzer 1991; Seligman 1992). A rhetoric of moral entreaty fashions appeals to freedom of speech, thought, and faith, the right to own property, the right to economic welfare, the right to clean environments, and so on. In social movements, moral understandings of right and wrong, good and bad, proper and improper are created, affirmed, and changed (Gusfield 1963).

Like their counterparts in the feminist, labor, and civil rights movements, those in the environmental movement typically appeal to issues of justice and rights to make their claims. At the end of the nineteenth century and the beginning of the twentieth century, for example, people organized in response to a perceived need to protect and conserve species and habitats (Schnaiberg 1980; Nash 1989). Their moral appeal was based on accepting a transition from liberalism’s natural rights philosophy to a “rights of nature” ethic (Nash 1989, 7). More recently, appeals to environmental justice and the more provocative charge of environmental racism direct attention to unequal distributions of risks (Szasz 1994).

The environmentally ill, however, are organizing around more than a populist appeal to moral or ethical rights. Specifically, people who believe they are made sick by the production, use, and disposal of modern material culture are fusing a moral appeal for safe environments with a popular appropriation of biomedical knowledge to make a particularly persuasive claim on institutions to change or
modify their behaviors and policies. We find this development interesting for its representation of the complex exchange between citizens, expert knowledge, and expert systems in the waning years of the twentieth century.

If Locke could write in the seventeenth century that the “rights of man” would be assured by joining the ordinary person to “instrumental rationality,” by the nineteenth century ordinary people were effectively separated from technical ways of knowing the world. From the early twentieth century to the present, appeals to human rights were increasingly dissociated from rationality and its instruments (Touraine 1995). Expert knowledge was the province of the professions, licensed and protected by the state (Giddens 1990).

Expert systems emerged, mysterious and complicated, almost magical, artfully manipulating weights and measures, microscopes, slide rules, tests of all sorts—in short, the instruments of rational knowledge. Social movements relied on ethical and moral, not scientific, appeals to lobby for change. If an expert opinion was needed, the best a person or group could do was to hire an expert to represent their interests. Sociologists wrote about “symbolic politics” (Gusfield 1963, 180) and “rhetorics of transcendence” (Stewart, Smith, and Denton 1984, 121). Ordinary citizens could certainly appeal to scientific ways of knowing to assist them in constructing a rhetorical message, but they were not themselves claiming to know something new and legitimate based on their use of scientific knowledge. Separating citizens from instrumental rationality ensured that modernity would succeed, as Alain Touraine (1995) writes, in separating the “world of nature, which is governed by the laws discovered and used by rational thought, and the world of the Subject” (57).

But nature and the Subject cannot avoid one another in the embodied narrative of EI. Environmental illness is a story constructed by nonexperts about human bodies in somatic dissent against a material world saturated with commodities promising to make life easier and healthier, and the body itself more attractive. It is a survival story and thus ultimately a moral story, one told in a language of instrumental and rational action.
A reasonable and final question to ask of these narratives is whether they are true. A practical epistemology may or may not meet medical or scientific criteria of truth; its standard of validity is more immediately sensible and can be summed up in the question Does it work? or Is it useful? A practical epistemology reclaims ordinary experience as a pathway to knowledge. Based on immediate, tangible, and sensory evidence of cause and effect between bodies and environments, EI reconciles the self and the body. It restores a sense of order between the cognitive, emotional, and somatic parts of a person. In short, while it is not a cure, the story of EI may help a person to heal.

“I sometimes wonder if MCS is real,” a mother and housewife writes, “I mean, a lot of people think it isn’t. But then I think, ‘Well, are you better now than you were when you didn’t know what was wrong?’… If I’m a kook, okay, at least I feel better.”

“When I read about environmental illness,” recalls a retired engineer, “a light went on in my head and I said, ‘Ha-ha, I’m not crazy.’ Knowing what was wrong with me has been important. I can explain myself now.” A former advertising executive is more to the point: “MCS is not a cure, it is a way to stay alive and not just physically alive. I mean psychologically alive.”

Staying “physically” and “psychologically alive” through telling stories about environments and bodies framed in the borrowed language of biomedicine is a pragmatic response to the question, Yes, but are these stories true? If a new body is emerging in society, however, it will need to satisfy more than the chemically reactive themselves. It must also be acknowledged in social and cultural spheres more encompassing than the self. We can glimpse the necessity for the public recognition and acceptance of a new body in the remarks of a professional woman describing how she explains MCS to others:

How I explain this illness to others depends first on how much time I have. If I only get a one-liner, I might actually say, inaccurately but usually effective, “Excuse me, but I’m allergic to your perfume or hair spray,” for example. If there’s a little more time, I’ll say, “I have respiratory” (or “breathing”) “problems which disallow any exposure to
ambient chemicals.” . . . If he or she inquires further, I explain, “I was poisoned by pesticides, asbestos, and other chemicals on several occasions. Having become chemically injured in this way renders me physically intolerant of chemical exposure.” I might provide an example: “Right now your shaving cream and the moth balls in the closet sting me every time I inhale.” The person will demonstrate a little shock, so I’ll reassure him or her: “It’s all right. Let’s move over by the window. That will mitigate the effect.” At this point, I may be asked to prove (though they’ll never use the word) I was poisoned, or the nature of the injury. More frequently I am asked, “Well, what sorts of things bother you?” I reply that it is not a matter of anything “bothering” me, but rather, that various categories of chemicals cause me pain. Then I’ll rattle off a list. I may also explain that I do not have to perceive any odor in order to be so affected, and will provide examples such as when, in a hospital just after a car accident, I was awakened from a double-dose morphine sleep by a spray of hair spray in the bed on the opposite side of a curtain in my room.

Sometimes people do want to understand better why those with MCS experience such pain and debilitation. With a highly educated person, I might present a combination of Bill Meggs’s neurogenic inflammation” and Iris Bell’s “limbic kindling” theories, leaning toward the former. Otherwise I might ask a person to imagine he or she had second-degree burns, internally, in the sinuses. “How might it feel,” I ask, “if you were without functioning cilia—or any cilia at all, if your mucosa were dried and cracked, with several cell layers of damage, so that chemicals could easily eat into deep layers of sensitive tissue; and if someone then put a drop of iodine or chlorine or formaldehyde on that area? And what if this happened over and over, at every breath?”

If the inquirer can’t understand intolerance of intermittent light, I explain that the electrical functioning of the brain depends on lipid-rich myelin sheaths surrounding nerves. Since there is an (autoimmune) antmyelin component to MCS, it could be that electrical impulses are more easily scattered. (This is upheld by gEEG studies.) Exposure to
EMR [electromagnetic radiation], including fields generated by fluorescent lights, could significantly affect brain electrical functioning where myelin is lacking. I present other reasons, too, with medical journal documentation, for why intermittent light may be deleterious.

Occasionally the listener needs to know prevalence, in which case I present the latest estimates that may be drawn from surveys by Bill Meggs, Iris Bell, and Claudia Miller. Usually these days, unlike at first, the listener will know someone who is chemically sensitive. “But he or she was also psychologically affected,” I will often hear (which I take as a compliment). I then explain the difference between psychogenesis and the manifestation of psychological sequelae; and urge him or her to be careful not to be the judge. It is the case that people who have been told repeatedly by society that they are wrong, that they are mentally, not physically, ill, will begin to believe it—and to act that way. To presume mental illness of MCS sufferers in each case results in further physical injury (through lack of protection from chemicals), further disablement, and therefore further cost to society. It behooves society to presume physical illness just as in this democracy we are committed to presuming innocence, but with much higher stakes, in this case.

This thoughtful and detailed account hints at the importance of others to the ratification of a new body. In the following chapter we take up the issue of ratification, framing it as a problem of representation. If a new body is going to be more than a sociopsychological resource for the chemically reactive, it must be represented in reconfigured social relationships, new public and corporate policies, issues of litigation, and changes in the market, as well as, of course, sociological accounts such as this one. As we will see in the next two chapters, the environmentally ill body is carving out a quite visible, if still limited, presence in late modern society.