Bodies in Protest

Floyd, H. Hugh, Kroll-Smith, Steve

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Bodies against Theory

What has been called the “search for knowledge” might be better and more modestly regarded as a dialogue—among ourselves, and between ourselves and nature—from which we learn whatever aspects of nature and ourselves we may need to know in order to go on surviving.

(Bickerton 1990, 231)

A striking feature of the interviews we collected was the common activities among people who would later identify themselves as chemically reactive. Like sleuths in search of clues, these people interrogate their material environments as possible perpetrators of disease. In systematic fashion they look for relationships between symptoms and specific places and things. Truth for those with MCS is not sought outside of a rational practice.

If the initial stage of EI is accepting the unsettling idea that formerly safe and nurturing places are now health hazards, the second move a chemically reactive person is likely to make is a calculated reassessment of the boundaries between what must now be considered dangerous and what can be approached as safe. In identifying environments that cause sickness and classifying specific symptoms with specific consumer products and chemicals, the environmentally ill
organize both their thinking and their routines, creating the possibility of coexisting in a world that has now become a much more dangerous proposition.

A graduate student majoring in business administration recalls:

I am an orderly person and did not want to panic when I started to get sick from what seemed like everything. I remember walking around my apartment coaching myself to get a grip. . . . I found a legal pad and started to list things that seemed to make me sick and how I would get sick, like hives, joint pain, indigestion, things like that.

A legal secretary imagined her body was “a Geiger counter and I listened for a tick, tick, tick when it got near something it reacted to.” A retired dentist recalls becoming “a student of my body. Like I said, ‘Okay Mr. body, you me tell what I need to do,’ you know, to protect myself.” Lynn Lawson, a professional writer, developed what she calls “Lawson’s Second Law: You have to be your own personal environmental protection agency. . . . You have to learn how to protect yourself” (1993, 318).

In addition to establishing correlations between places, things, and their bodies, many people also associate specific types of reactions with specific environments and consumer products. Recalling her initial experiences of various changes in her body in relationship to specific places and chemical products, a massage therapist writes:

I walked into a church basement and started feeling spacey. My balance was affected and my gait changed. A friend helped me get out. When I hit the fresh air, I started crying. After five to ten minutes of fresh air, the crying was under control, but I experienced fatigue and a deflated mood.

An old oil tank was removed from my house. In the process, oil fumes were released into the air and some oil was spilled onto the cement floor. I spent the week climbing the walls, feeling like my seams were fraying on the inside. This reminded me of when I lived near an oil refinery. Whenever I went outside, I felt the same way. At that time, I
didn’t understand what was happening and called it “anxiety.” This time, when the tank was removed, I knew why I felt the way I did.

I had a mole removed from my face. A local anesthetic was used. Fatigue, depressed mood, digestive disturbances, and dizziness hounded me for several days. Five days later, when the stitches were removed, the doctor kept an isopropyl alcohol-soaked pad on the area. . . . This brought on a crying spell. Several hours later, I went to the emergency room with severe left-side chest pain involving my left arm. . . . Tests showed no lung or heart involvement. . . . I consider this to have been a delayed reaction to the alcohol exposure.

These accounts illustrate both a product of thought, a nascent theory of the body and its relationship to the environment, and a process of thinking. The product and the process, of course, are not unrelated. We examine them both in this chapter, attending first to the process of thinking. Thinking typically proceeds on the basis of at least a few unstated assumptions about how knowing is possible. At the risk of seeming to read too much into the illness narratives, we identify some of the premises that structure the way the chemically reactive approach the problem of theorizing their bodies. Next, several accounts from the chemically reactive tell a remarkable story about causal relationships between recalcitrant and disorderly bodies and the specific environments and consumer products they encounter.

Experiences, Bodies, and the Return of the Subject

What can be said about the process of theorizing EI thus far? The accounts already cited in this chapter and those to come imply a simple but significant observation: a baseline premise for theorizing MCS is a belief that human experience is a valid way of knowing. This premise might strike many readers as lacking in imagination. But it assumes considerable importance when we remember that, in Beck’s words, “experience—understood as the individual’s sensory understanding of the world—is the orphan child of the scientized world”
Valid and reliable knowledge in the modern world is the product of experimental science and, pointedly, not subjective experience. People, of course, can trust their senses as sources of knowing; when they do so, however, they cannot claim to know something scientific or medical about themselves or their world. To refer to an observation or thought as subjective is to remove it from serious consideration as a source of expert knowledge. As a theory of disease, however, MCS begins with experiences that oppose biomedical theory. It is almost as if the chemically reactive body is organized against medical science, a body against theory, as it were.

Interpreting the importance of somatic experience to the chemically reactive begins with a simple observation: they do not approach their dilemmas as poststructuralists, assuming their somatic states are products of diverse discourses, symbols that become things. Rather, they pursue an explanation of their sick bodies in the language of naturalism. Like Kenneth Burke’s black holes, EI is what it is as it is; it merely has to be empirically identified (1989, 60).

Furthermore, people who experience changes in their bodies’ capacities to exist in common and customary settings believe their bodies exist independently of themselves as thinking beings. An electrician in a sewerage treatment plant is challenged by his disease: “I’ve always been one to figure things out. Now I’m trying to figure my body out, like we’re playing a game of chess. . . . Today I’m winning but I might be losing tomorrow.” A former dentist recalls his first several months of living with EI: “I kept saying to myself, ‘You’re not crazy. You are blessed with a good mind. Figure this thing out.’ I said something like this to myself every day.” “Like everybody, I took my body for granted,” remembers a hair stylist; then “it was like my body became this big old Rubic’s Cube, a puzzle I was determined to solve.” Distancing herself from her illness to gain some control over it, a woman with a degree in psychology writes, “I do not identify myself as chemically sensitive—my body is chemically sensitive and that identifies me!”

While Bryan Turner (1984) can end his lengthy and important
inquiry into the body by admitting that in writing it he has “become increasingly less sure of what the body is” (7), a person whose body is responding in extreme and unexpected ways to what were once known as safe places must be sure of how the body works, what makes it sick, and what makes it well. Most of us are aware of a distinction between our selves and our bodies. For the chemically reactive, however, acknowledging the distance is a first step toward thinking deliberately about their bodies.

Finally, people with EI experience their bodies as sources of unmediated knowledge; importantly, they act toward that knowledge as if it were rational, that is, legitimate. A person can know his self, as opposed to his body, as Mead (1967) reminds us, only “indirectly, from the particular standpoints of other individual members of the same social group or from the generalized standpoint of the social group as a whole to which” he belongs (202). The immediate experience of the body, however, is direct, requiring only consciousness to be real. Our first-order relationship to our bodies, in other words, occurs in the absence of significant social symbols; it is a sensory relationship above all. Somatic pain or pleasure does not require the immediate ratification of others. What typically does require confirmation, however, is how a particular somatic experience is classified and explained. Aggregating, classifying, and explaining bodies has long been recognized by the modern state as an important exercise in control. Foucault (1973) thought it the most penetrating form of modern control and located its most incisive expression in the emergence of medical science. He identified “a spontaneous and deeply rooted convergence between the requirements of political ideology and those of medical technology” (38). The more sophisticated medical technology becomes, the less necessary it is to listen to the person whose body requires attention.

The erosion of the subject in the professional practice of medicine is neatly captured in the now standard social science distinction between illness and disease. “Disease,” according to a standard textbook in medical sociology, “refers to a medical concept of pathology
... clinically defined by the medical profession." Illness, on the other hand, is the experience of “health and ill-health and is indicated by the person’s reactions to the symptoms” (Bond and Bond 1986, 200). The authority to medically evaluate a body and pronounce it diseased is strictly limited to a group of licensed practitioners. In spite of the authority of the medical profession to legislate disease as if there was a body but no person, a diseased body is animated by a subject. While this fact might irritate some physicians, it was an open invitation to social and behavioral scientists. Subjects, it was decided, would experience their diseases as illness behaviors and perceptions, topics ideally suited to the human sciences. In short, while bodies would have diseases, subjects would have illnesses.

This neat separation of the subject from the body renders the personal experiences of bodies unsuitable for biomedical theories. And to be sure, separating bodies from persons is by no means universally decried. To the contrary, it is reasonable to assume that laypersons would not ordinarily dissent from a practice that renders them, simply, bodies if such a practice, however distasteful, results in a cure.

Most people in the second stage of MCS—those who are struggling to identify, classify, and reorder their bodies in relationship to places and things—are also seeing physicians. Among their first moves when they realized that something unusual was happening to them was to seek medical attention. With few exceptions, however, the diagnoses and treatments are not working. Indeed, as we will see in the next chapter, medical treatment often intensifies distress rather than relieving it.

But the important point here is the simultaneous activities of the chemically reactive who are both visiting physicians and working independently of them to determine the causes of their discomfort. People in the nascent stages of MCS often tell their physicians stories about the strange reactions of their bodies when exposed to a seemingly endless array of environments and consumer products. Most doctors, however, cannot affirm the bizarre, queer stories they are told. They are more likely to act like good doctors who try to fit the
diagnostic signs they are observing into some recognized disorder, thus routinizing what at first glance is likely to appear anything but routine.

A former hair stylist provides this account:

I wanted my doctor to tell me what was wrong. To prescribe something and get me well again. But all of the things he called my problem, “adult-onset asthma,” “possibly Epstein-Barr,” and things didn’t help. . . . so I kept worrying, testing my body, like I would say to myself, “Okay, now you are going to walk down the dog food aisle in the grocery store and you’re going to see how you feel.” I planned to walk down every aisle of our grocery store one weekend and write down how I felt. I only made it down three aisles, though, before I got too sick. My husband thought I was crazy. He told me it wasn’t a very good test because if I was reacting to anything (in one aisle) it would be jumbled up with something else (in another aisle). . . . My next plan was to go down one aisle a day and keep a diary of my reactions.

A disabled seamstress writes:

I had chest constriction. Blood oxygen dropped to 50. The treating physician swore I had a blood clot in my lung. Or heart disease. Guess what? No evidence of any of these. It was a chemical reaction, I told him, but he told me it wasn’t. He couldn’t figure it out.

A college professor recalls his early visits to his family doctor:

It got to be a ritual. Every time I sat on his examining table, I would tell him that I thought this or that was making me sick. He would look puzzled, shake his head, and tell me I looked fine. I would tell him I might look fine but I feel terrible. He would tell me the tests were negative. I respond with, “Well, we need to make up some new tests.” Both of us thought my symptoms were strange. The difference is I believed what I had was real and he wasn’t sure he believed me.

Perhaps his physician couldn’t believe. If every way of seeing is also a way of not seeing, biomedicine is an explanation that stops well
short of an inclusive view of the body, and certainly a view of the body
that includes the active voice of the subject constructing outlandish
claims about environments and bodies. Environmental illness, it
would seem, is an anomaly, a somatic experience that according to
prevailing biomedical theory one should not have.

Anomalies periodically occur in theoretical physics and chemistry
with no apparent side effects for the ordinary person (Kuhn 1970).
When a human body becomes an anomaly for medicine, however, the
effects can be experienced as quite real. An operations clerk writes:

Upon two occasions I found myself using the emergency room of our
local hospital. Upon mentioning my problems with chemicals, I was
either ignored or—as one suggested—it was all bunk and proceeded to
make fun of my situation and thought I was nuts. Another time I had to
have minor surgery in the emergency room and tried to explain to the
nurse that the disinfectant she opened up bothered me. Again, I was
ignored.

Not all respondents who consulted physicians found them hostile
to their nascent theories. In a limited number of cases, people visited
doctors who knew something about the controversies over chemicals
and the body. A few of them affirmed their patients’ work to reclassify
their life spaces and manage their symptoms. A housewife writes: “I
count myself lucky. The first doctor I went to told me about environ-
mental illness. She said it was something new and it sounded like I
might have it.”

Her story is unusual, however. Only 9 people among the 121 we
interviewed reported visiting physicians who respected their accounts
and worked with them to solve the puzzle of EI. In these unusual
cases we see how some experts, for whatever reasons, collude with
nonexperts, supporting their theories in spite of the resistance of the
profession. We will revisit this process in more detail in the final chap-
ter. It is sufficient for the moment to note it and to remember that
while it is the exception rather than the rule in our interviews, it can be
an important variation in the separation of expert knowledge from
expert systems, namely, the separation of an expert from the system. But whether or not a physician agreed with the initial cause-and-effect reasoning of a person whose body reacts in untoward and debilitating ways to ordinary environments, the point is that this person is making concrete correlations between somatic experiences and putatively benign places and things. “What is real for me,” writes a book salesman, “is what I am going through, what I feel like, not what other people tell me I should be feeling, or not feeling.” A psychologist with EI writes:

My degree is in psychology and if I had encountered a client who made claims such as I do, I would have no doubt the person was mentally ill. This illness is so bizarre-appearing and so unbelievable that I have trouble believing it myself! It is only that I experience it myself that allows me to know the truth of it.

A housewife is more direct: “I get dizzy . . . around paint solvents and usually right after I get big, massive headaches. If I get away from the solvents I’m fine. . . . Are you going to tell me it’s not the solvents?”

The truth of MCS begins with ordinary people who experience untoward changes in their bodies. If modernity “actively eliminates the idea of the Subject” (Touraine 1995, 27), replacing the unique and personal qualities of the knower by what is objectively known, it might be said that the Subject is returning in the form of a sick body. Knowing that begins with the sensations of the body rekindles an epistemology that is anything but Cartesian, namely, I feel, therefore I think. When bodies resist being the objects of biomedical theory and somatic experiences become a source of objective knowledge, it is not difficult to imagine a fault line in the foundation of modern rationality.

For the chemically reactive, knowledge about their sickness originates with embodied experiences that are typically tracked, classified, and arranged into meaningful clusters. It is a practical epistemology insofar as it joins experiences to practices and is mindful of the results.

A former intensive care nurse describes what she would say to a
person who wanted to understand this stage in the process of becoming multiply chemically sensitive:

I would . . . ask the person to take a notebook and for one day write down the chemicals found in every item they eat or drink that day (as listed in the ingredients). Ask them to list every item in their home that is scented, every cleaning product and the chemicals they contain. Chemicals they encounter in stores, gas stations, day cares, etc. What pesticides they used and how often they used them. . . . Then ask them to look up the exposure limits of each and the accumulative effect.

What follows are accounts of how people reorganize their thinking about their bodies and environments by a meticulous, detailed process of assigning somatic responses to ordinary chemical products and routine places. In the language of statistics, associations quickly become correlations as their trial-and-error methods yield a more manageable, but also more circumscribed, world. These several accounts illustrate the obvious fact that truth for the environmentally ill is not being sought outside a deliberately rational practice, though that practice originates, some might say heretically, with human experience.

**Reordering and Reclassifying**

An attorney describes her first attempts to understand how her body might be responding to her house and to control her exposure:

Rob and I finally started going through the cabinets. When I would open one and the smell would just overwhelm me, I’d shut it and ask him to get rid of what was in there. . . . We had stuff in the pantry, but that doesn’t smell. It was in the bedroom. We have all these hand creams. Like every Christmas somebody would stick some sort of bath oil in your Christmas stocking. . . . So we literally filled up bags of stuff and gave it to my mother and anybody who wanted it. . . . I would open the bathroom cabinet and say, “Well, Rob, I guess some of these towels were washed with fabric softener. I can still smell something. . . . We
got rid of baby powder, shampoo, herbal shampoo, and stuff like that. . . . Rob got rid of his aftershaves and colognes. . . . There’s no more Comet to clean with. No more Windex or other things like that. . . . I visited my parents and when I was using their bathroom I had to come out and say, “Dad, what is in your bathroom? I can’t even go in there.” And he said, “Oh, I put some Pine Sol in the toilet. Is that going to cause you a problem?” I said, “It’s driving me bonkers!”

A professional writer, Lynn Lawson (1993), recalls her initial illness experiences with her house and her day-to-day routines:

First . . . I wanted to clean up my house and lifestyle. . . . My husband and I had our unvented gas kitchen stove removed and an electric one installed. We bought air filters that removed chemicals, one for our living room, and one for our bedroom, and one for our car. We started driving our car with windows closed, the filter going, and the ventilating system on “recirculate.” We try to leave ample space between our car and other cars’ exhaust pipes. My husband reads our daily paper first, then puts it in a zippered nylon mesh bag and “bakes” it for forty minutes in our electric dryer vented to the outside, which outgasses chemicals in paper and ink so that I can read it. . . . I threw out . . . petroleum-based products. . . . I put away my electric blanket (the heated wire gives off fumes) and sleep under down, wool, or cotton, as pure as possible. Essentially it was back to the thirties—to the products that I remember my mother using. (28)

In addition to becoming aware of local environments as possible sources of distress, the chemically reactive are likely to use a “first-this-and-then-that” mode of reasoning to classify somatic changes in relationship to specific places and things. Some respondents reported a similar somatic reaction to a wide array of places and things. A legal secretary and folksinger first lists an array of built environments and commercial products she correlates with a common symptom pattern. Among the things that trigger her symptoms are the following:
Petroleum and many of its by-products, herbicides, perfumes, chemical cleaners, brand-new books, all synthetic materials, hospitals, recently renovated rooms, buildings heated with oil furnaces, places with air-conditioning. . . .

The first symptoms I notice are usually a growing nausea and an increasing tremor in my entire body. My head starts to pound and I begin to feel anxious and jumpy. Then an overwhelming fatigue sets in. As all these symptoms worsen, my jaw clenches and my shoulders and neck tense up. After a while I feel like all my insides want to leap out of my body. . . . I feel extremely uncomfortable and extremely ill.

An art history catalogue editor first lists her symptoms, ranked according to whether they are chronic or occur occasionally because of unusual exposures, followed by the places and things that make her sick:

Symptoms: chronic chemical bronchitis, . . . nasal congestion, digestive problems, circulation problems in hands and feet, synovitis in one toe and possible hip joints, extreme sensitivity around root surface of teeth . . . irritability, impaired memory, recent allergies to dust mites and mold. The above complaints are unchanging; with prolonged exposure, I experience extreme fatigue, flulike feeling, pressure on sinuses, headache, and neuromuscular twitching that interferes with sleep.

The following are some of the places and things that make her sick:

retail stores selling clothing, dry cleaners, beauty salons, new cars, gas stations, any new building containing emissions from carpeting . . . vinyl, upholstery, varnish, office copiers, laser printers, Scotch tape, felt-tip markers, nail polish, hair spray.

Other respondents were more precise in their inventories of environmental triggers and somatic reactions, drawing exact correlations between one or two offending agents and a specific reaction. A woman with a bachelor’s degree in English who worked as a typesetter for many years recounts her taxonomy:
Gasoline causes anger and pain in the head. . . . Wal-Mart causes gastrointestinal pain and I get very spacey to the point of not even being able to remember my name or do what I went in there for. . . . Fabric softener causes severe back pain so that I’m not even able to walk at times. Living in Louisiana causes back pain and my body cannot hold a chiropractic adjustment . . . because of the massive chemical exposures.

A products designer writes: “When I am exposed to chlorinated solvents . . . I first get stabbing pain behind my eyeballs, my vision blurs, my brain starts to swell. . . . When I am exposed to chlorinated hydrocarbons, however, I have a different set of symptoms.”

A former advertising executive is considerably more systematic in her classification scheme. She listed fifty-two separate “Chemicals and Irritants” on the left side of the page and her reactions on the right side. Consider an excerpt from her taxonomy of environmental agents and somatic responses:

<table>
<thead>
<tr>
<th>Chemicals and Irritants</th>
<th>My Reaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Polyester</td>
<td>Throat tightens</td>
</tr>
<tr>
<td>Clothing dyes</td>
<td>Skin crawls</td>
</tr>
<tr>
<td>Newsprint</td>
<td>Body vibrates</td>
</tr>
<tr>
<td>Computers</td>
<td>Difficulty concentrating</td>
</tr>
<tr>
<td>Magic markers</td>
<td>Nasopharyngeal passages irritated</td>
</tr>
<tr>
<td>Synthetics in clothing</td>
<td>Body vibrates</td>
</tr>
<tr>
<td>Electricity</td>
<td>Stimulates bladder</td>
</tr>
<tr>
<td>Forced-air systems</td>
<td>Pain in neck gland</td>
</tr>
</tbody>
</table>

This same woman goes on to describe how she makes use of her classificatory scheme to sort out the risks she is likely to encounter in accomplishing an ordinary task:

Most people take buying a new watchband for granted. Your old one wears out. You stop in at the local jeweler and you select a new one. The jeweler attaches it to your watch, and you walk out and forget about it. I have learned to take nothing for granted. I ask myself, first, whether this is a day when I can tolerate the environment in the street
on the way to the jeweler. If yes, will the air in his store knock me out? Can I tolerate the air long enough to pick out a watchband? . . . Will I react to the chemicals in a leather band? Can I tolerate the plastics and the resins in a man-made watchband?

A former chemical engineer who now makes a living as a substitute teacher has also constructed an elaborate taxonomy of environmental agents and somatic responses:

- **Auto exhaust**: A traveling pain that might first be in my leg, then elbow, etc.
- **Tertiary amines (ammonias)**: Low-level paranoia
- **Hexane**: Fear
- **Natural gas**: Giddiness at low concentrations, grogginess at higher concentrations
- **Fertilizers**: A feeling that the top of my head is coming off
- **Food additives**: Pain in joints

After constructing his taxonomy, he describes a person entering his office as he reads what he has just written: “I am proofreading now, and someone just came in who is wearing perfume, so my thinking ability is reduced as the skin on my back and my lower back is getting tight.” Noteworthy in this short aside is its matter-of-fact tone, expressing a “first-this-and-then-that” logic with not so much as a hint of surprise. “Exposure to perfume equals reduced thinking ability” is one of the many ways of correlating bodies and ordinary commercial products that for this person seem rather unremarkable.

A retired file clerk constructs her own taxonomy of unexceptional consumer items and somatic symptoms. Among her many correlations are the following:

- **Cleaning solvents**: Insomnia, memory loss
- **Most shampoos**: Rash on face and muscle pain
- **Plastic phones**: Memory loss, headaches
- **Answering machines**: Burning in neck and shoulders
<table>
<thead>
<tr>
<th>Agent</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gasoline</td>
<td>Severe headaches, insomnia</td>
</tr>
<tr>
<td>Bounce fabric softener</td>
<td>Skin discoloring and nausea</td>
</tr>
<tr>
<td>Leather shoes</td>
<td>Shortness of breath</td>
</tr>
</tbody>
</table>

A former librarian develops yet another elaborate scheme, a portion of which is reproduced here:

<table>
<thead>
<tr>
<th>Agent</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aspirin, various drugs</td>
<td>Blood pressure surges, burning skin</td>
</tr>
<tr>
<td>Scented soaps</td>
<td>Sore throat, severe headache, sometimes congestion, emotions</td>
</tr>
<tr>
<td>Plastics</td>
<td>Headache, eyes dry, burning throat, muscle pain/spasms/weakness, thirsty</td>
</tr>
<tr>
<td>Street work, asphalt, treated poles</td>
<td>Sore (loose) teeth, temperature rise, blood pressure surges, headache, burning skin, stomach pains, cramps</td>
</tr>
<tr>
<td>Toxic plastic phones</td>
<td>Headaches, facial numbness, muscle/joint pains</td>
</tr>
</tbody>
</table>

Not everyone is as precise as the first several excerpts would suggest in relating specific agents with specific somatic responses. Some people construct a more general taxonomy. “Malls,” a former seamstress writes, cause “breathing trouble, nausea, dizziness, headaches. fibromyalgia, chronic fatigue syndrome, which is extreme,” while “church” causes “severe respiratory distress.” A marine transport dispatcher writes, “Houses with vinyl siding are dangerous for me. Even driving by one can cause my eyes to burn. Walking by one I am likely to lose my balance and stumble.” He continues, “If I walk into a backyard with a gas grill I often experience memory loss, even if the grill is not working.” A retired army colonel developed a rating system to catalogue his varied somatic reactions to environments and his body’s capacity to withstand the “insults”: “0 to 5 is my ‘insult scale.’ I figure my body can be only so insulted before it breaks down. . . . Say I’ve been exposed to two 4s and one 5 in the morning and I am invited to
someone’s house that evening for dinner. I will usually decline because I will likely get sick if I am exposed to any more insults.” Among the twelve 5s on the “insult scale” are “traffic jams,” “visits to the Veterans Administration office,” “shopping malls,” and “filling my car with gas.”

The body we encounter in the several narratives on reordering and reclassifying is not the body we encounter in standard biomedical theory and practice. The primary differences are in the perspectives or vantage points from which bodies are considered and in the strategies for classifying them. Consider first the idea of vantage point, or a stance for viewing bodies.

**A Return to the Body’s Surface**

What is essential to know about a body for a person with MCS is what is generally ignored by biomedicine—specifically, its situated relationship with houses, schools, parks, stores, churches, hospitals, shopping malls, and the thousands of commercial products found in these and similar places. The accounts of reclassifying and reordering share the idea that bodies are known in their relationships to environments. A person with MCS examines points of intersection between her body and those places and things it is encountering. She is interested in the surface of her body and its points of contact with material culture.

Biomedicine’s gaze, on the other hand, is directed from the physician to the body, and only rarely, if at all, is the relationship between the body and the environment considered in clinical terms. Professional medicine, Foucault reminds us, “project[s] upon the living body a whole network of anatomo-pathological mappings: to draw the dotted outline of the future autopsy. The problem, then, is to bring to the surface that which is layered in depth” (1973, 162). Echoing Foucault, Young writes, “Illness in Western society is viewed from an ‘internalizing’ perspective. The relevant causes are immediate and localized within the body” (1976, 148; see also Freund and McGuire
Accordingly, the body in biomedicine is defined in the absence of physical, chemical, or social environments.\(^3\)

In reordering and reclassifying their relationship to material culture, the environmentally ill are shifting attention from an interior view of the body to the spaces where bodies and places intersect. For them this is a practical, indeed necessary, shift in perspective. We don’t believe the chemically reactive would argue that their version of the body should replace the internal body of biomedicine; clearly, important things occur in the interior of the body. But they would argue for the legitimacy and the complementarity of a version of the body as a porous surface, absorbing the environments it touches. For them, we might say, the truth about the body is that it is many things.

Constructing a practical epistemology is, after all, not a search for universal truth but a deliberate attempt to know something important that is at once empirically and psychologically self-legitimating. “YOU ARE WHAT TOUCHES YOU,” announces a flier from the Healthy Environment Info and Referral Service (January 1996), an MCS support group. The announcement continues:

We aren’t only what we eat, we are also what we breathe and touch…. Our bodies are part of the overall environment exposed to many toxic elements. . . . Buildings and monuments everywhere are deteriorating from the effects of pollution; our bodies eventually react in the same way.

Both a human body and a polished stone shaped into something worthy of remembering can deteriorate at those points where they intersect with dangerous environments. Some observers might find it spurious to compare bodies that appear to get sick when exposed to places and things routinely identified as safe with monuments exposed to acidic rain. The chemically reactive, however, experience their symptoms as legitimate somatic complaints and thus know there is a connection between their disabilities and local environments.

The studied focus of the environmentally ill on the places and things touched and absorbed by the surfaces of their bodies invites
comparison with an earlier period when the body’s exterior was a source of considerable medical and popular attention. From the 1940s to the 1960s, bodies were imagined as vulnerable to an endless number of microorganisms. Germs were pictured as swarming on the surfaces of material culture—tables, drinking glasses, clothing, and so on—looking for a path into the interior of the body. “Enormous attention,” writes anthropologist Emily Martin, “was devoted to cleaning surfaces” that would come in contact with the body, and, in turn, cleaning “surfaces of the body” (1994, 24). The surface of the body was viewed as extremely vulnerable to invasion by germs. “It was the opening left in the body’s surfaces—a literal physical breach—that would allow disease to get in” (27).

By the late 1960s, however, biomedicine was focusing its research attention on the immune system, and popular culture was singing the praises of “Your Magic Doctor,” or “Our Internal Defender” (Martin 1994, 51). Modern society had discovered a new champion. (It is worth recalling that the first academic department of immunology opened its doors in 1972.) A pathogenic environment could now be rendered innocuous by a robust immune system. Indeed, germs rarely overwhelmed a healthy immune system. Rather, like an invincible army, the immune system seemed to get stronger as it repelled its arch-enemy. With something inside the body to protect it from disease, we could be less concerned with the body’s surface and, for that matter, the cleanliness of the environments it encountered.

The emergence of MCS is once again focusing cultural attention on the surface of the body and surrounding environments, but with a considerably different emphasis than the personal hygiene movement of thirty years ago. Most noticeable is the shift from germs to chemicals as disease-causing agents. Ironically, the very same cleaning products that were advertised to protect against germs, such as Lysol, Borax, and Old English Lemon Oil, to name only a few, are now believed to be the sources of disease. For the chemically reactive, a spotlessly clean environment is probably a genuine health risk.

While both the personal hygiene movement and MCS direct atten-
tion to the surface of the body, there are noticeable differences in their respective definitions of risky environments and marked differences in their practical consequences. Dirt, dust, flies, and other germ carriers are unfortunate by-products of entropy and nature, offensive, to be sure, but manageable. The environment of the personal hygiene movement could be washed off the body or neutralized through disinfectants. While countless germs created their own versions of extreme environments, they were nevertheless manageable. The environment of MCS, however, is considerably more insidious, dangerous, and political. Now the very things that protected us from germs make us sick. A chemically reactive person is much less likely to be concerned with dirt than with the commercial products used to remove it. The environment of MCS is literally, to borrow from Giddens (1990), “a manufactured risk.” If the personal hygiene movement and its culture of cleanliness helped to create a market for cleaning products that in turn created capital, MCS accuses a capital-producing society of also being a disease-distributing society.

This brief excursus into the pathogenic environment of the personal hygiene movement and its contrasts with the chemically contaminated environment of MCS underscores the importance of medical movements in shaping the way people think about their bodies and environments. And it reminds us of the importance of where in society a movement originates. A professional initiative, the personal hygiene movement configured the authority of medicine with the good offices of federal, state, and local governments, educators, and the prestige presses to construct a persuasive machinery of knowledge and action. The goal of this massive mobilization was to change—control, if you will—such small and seemingly innocuous behaviors as the relationship of the hands to the mouth.

Multiple chemical sensitivity, on the other hand, originates in the perceived failure of the medical profession to explain or acknowledge new and untoward experiences of bodies and environments. Compared with the personal hygiene movement, its goal is considerably more difficult to achieve. The chemically reactive not only must ask
others to change routine habits but also must convince powerful institutional others that such changes are warranted—that a new disease is changing the relationship of bodies to places and things typically believed to be safe. Changing the way institutions think, as we will see, requires violating at least a few of their basic assumptions about knowing.

**Violating the Generic Body Assumption**

A second and related difference between the chemically reactive body and the official body of biomedicine involves the important question of how bodies are to be classified. To be reliable, it is assumed that a medical classification should account for more than one body. Call any poison control center, for example, and a technician will match an aversive agent with a cluster of symptoms. The underlying assumption is that a particular pernicious agent will trigger the same or similar signs and symptoms in all human bodies. When the Centers for Disease Control in Atlanta, Georgia, predicts the particular viruses likely to cause the flu in a coming season and concocts a vaccine, it assumes it is protecting a generic human body. Finally, when a doctor examines a patient, she approaches the body confident that it will be sufficiently like other bodies to classify it as sick or well using standard diagnostic measures. And, if needed, she can prescribe a treatment based on pharmaceuticals that are manufactured as if human bodies are more alike than different.

Perhaps the most essential premise of biomedicine is the coherence and predictability of the body. While it can be short or tall, thin or fat, ugly or attractive, a body is ultimately knowable as a member of a class of bodies. Without the assurance of this premise, biomedicine as a theory and a profession is at risk of defaulting on its promises to classify and control bodies, to render them uniform and knowable.

A striking feature of the narrative accounts found in this chapter, however, is the diverse and seemingly endless number of particular reactions that particular bodies have to particular environments and
the things found in them. Where there should be considerable duplication of trigger-response patterns among the chemically reactive if the body is as generic as biomedicine theorizes, there is, rather, marked diversity. “Just remember,” a writer with MCS notes, “we’re all different: what helps one does not always help the other” (Lawson 1993, 318). Hers is an admittedly troublesome counsel to most practicing physicians. How do those with MCS account for this anomaly? An English professor with severe EI writes:

My body is like yours and everybody else’s insofar as it will change with time, mature, grow old, and die. But my body is different from your body and your body is different from another’s body because each of us responds to chemicals in unique ways. I can’t assume that what makes you sick will make me sick, or sick in the same way.

A former typesetter explains further: “Each exposure is unique as is each individual (and the total body load at any given time) so you can’t lump them all together and come up with a blanket reaction.”

A concert musician writes:

My body is a complex chemistry; it shares some things with your body. But I have my own genes, my own cells, my own past as healthy and sick. How could my body be exactly like yours or somebody else’s. . . . I think we [medical science] spend too much time looking at how our bodies are alike and not enough time looking at how they are different.

“When people say ‘Hey, you’re nuts. I don’t get sick from watching TV or reading a newspaper,’” a grade school teacher has a ready response. “I say back, ‘Fine, I wish I had your body. Want to switch!’”

Read between the lines of stories told by the chemically reactive and a curious logic appears to be at work. While no two bodies are likely to respond to the same environmental trigger in the same manner, thus rendering bodies singular and diverse, it is assumed that most built environments and commercial products can be grouped together as a class and approached in the “what if” manner we encountered in chapter 3: “What if they are potential sources of debilitating symp-
toms?” If the body is a discrete entity in the social construction of EI, the extraordinary variability of modern material culture is grouped and classed as extreme, that is, dangerous and to be avoided or approached with caution.

Multiple chemical sensitivity becomes a practical epistemology, in part, through the concrete actions of people trying to cope with bizarre and untoward changes in their bodies. The matter-of-fact, almost prosaic, experiences of reclassifying and reordering their local environments are also organizing the minds of the chemically reactive. To paraphrase Geertz (1983, 155), those miseries they think to understand turn out be the minds they find themselves to have.

It is not difficult to see how the practical work of the environmentally ill is also a shift in the social location of theorizing bodies and disease. A more pronounced version of this shift is expressed in the often elaborate pathophysiology stories told by the chemically reactive to account for what specifically troubles them. As we will see, these stories are, among other things, clusters of words that work to persuade others that MCS is a genuine medical disorder. Not surprisingly, many of the words themselves are borrowed from the medical profession.