An Underworld Journey: Learning to Cope with Electromagnetic Hypersensitivity

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Abstract

Electromagnetic hypersensitivity is an illness in which exposure to electromagnetic radiation can produce a variety of physical symptoms. In most towns and cities, current levels of this radiation are more than a million times higher than previous levels under which life has evolved. People who are chronically exposed or have some other inciting event, or both, may become severely electrosensitive, thus becoming deprived of safe access to much of their surroundings. The immediate physical consequences of this malady can be devastating, and the secondary psychological challenges often are just as dire. This N=1 study by a physician with severe electromagnetic hypersensitivity describes the "underworld journey" of a person suffering from this illness. Key Words: Environmental anxiety/eco-anxiety—Environmental health.

oncerns about the health effects caused by electromagnetic field (EMF) exposure have grown markedly in the last decade. The BioInitiative Working Group (Sage & Carpenter, 2012), an international panel of 29 experts from 10 countries, authored a 1,479-page review of 1,800 studies that updated the science, public health, public policy, and global response concerning this health issue. The editors offer a digestible summary that highlights the most serious health endpoints linked to EMF exposure: an increased risk of childhood and adult leukemia, childhood and adult brain tumors, Alzheimer's dementia, and amyotrophic lateral sclerosis. Many other biological effects of EMF exposure are described in the report's 24 technical chapters.

Included in the BioInitiative report is a review of studies focused on electromagnetic hypersensitivity (EHS), a disorder occurring in a small percentage of people who develop symptoms when exposed to EMF levels tolerated by most people. Chemical sensitivity (CS) is a related disorder in which people become symptomatic when exposed to a variety of chemicals. Together EHS and CS are often referred to as environmental sensitivities (ES).

Belpomme et al. (2015) completed the most comprehensive study of ES, investigating 1,216 people: 71.6% with EHS, 7.2% with CS, and 21.2% with both. They found abnormalities in a multitude of physiologic markers, which prompted their conclusion that these sensitivities can be objectively characterized and diagnosed and "appear to involve inflammation-related hyper-histaminemia, oxidative stress, autoimmune response, capsulothalamic hypoperfusion and blood-brain barrier opening, and a deficit in melatonin metabolic availability" (p. 251). This evidence augments previous work by Johansson (2007) that documented EMF-triggered mast cell degranulation with the release of histamine, heparin, and serotonin, and work by Blank (2012) showing that EMF exposure can cause the production of stress proteins consistent with a major stress response.

Some still consider EHS and CS to be psychosomatic conditions rather than true sensitivities, in spite of mounting scientific evidence to the contrary. This view is reflected in the name "idiopathic environmental intolerance" (IEI)—*idiopathic* being a medical descriptor for diseases without a known cause. Gibson (2016) argues that the labels of ES, EHS, and CS reflect an environmental cause, while IEI suggests "a more random, individually situated condition that paves the way for psychologizing people's illness and maintains denial regarding the presence of the condition" (p. 131). As one example, Hausteiner et al. (2007) ask whether IEI is a delusional disorder. "In most cases," they answer, "the external symptom attribution to

chemicals has the character of an overvalued idea. An overvalued idea is a strongly (but not to a delusional degree) held preoccupagtion that is unreasonable given the evidence available; but there While it's possible that a small number of people presenting with ES symptoms may have a psychosomatic condition, studies like that Eby Belpomme at all confirm that many people it.

by Belpomme at al. confirm that many people do have a true sensi- $\stackrel{\sim}{\mathbf{L}}$ tivity leading to measurable biological changes.

To Belpomme's 1,216 cases, I add my own N=1 "study," a personal review of what it's like to succumb to a profound physiologic disorder further complicated by a near-total loss of safety in the physical environment. I do this, in part, to demonstrate how be-Ecoming hypersensitive, either to EMFs or chemical toxins, can result in a primary physical illness with profound psychological of EHS.

Gateway

In 2010, 1

Follow me, then, as I describe a descent into the underworld¹

Gateway to the Underworld: Overwhelm

In 2010, I suffered a serious brain injury from carbon monoxide poisoning. I improved dramatically in the first weeks of recovery and then more slowly over many months, only to begin worsening Ξ in 2013. I had worked as a hospice physician for 25 years and as a wilderness guide for 10 years—two contrasting lifestyles that helped reveal the source of my problem. I would feel fine while in the wilderness, only to feel poorly soon after returning home. Something in my hometown was making me sick, but I didn't know what. Being a doctor, an empiricist, I had many hypotheses, but I couldn't confirm any of them. In the space of weeks, my body then became seriously ill: headaches, fatigue, mental slowing, ringing in the ears, insomnia. I began stumbling down a path plummeting into the darkest of terrains.

As it turned out

As it turned out, I had to get that bad to figure out what was happening. A repeatedly severe reaction to a new Wi-Fi system at work created a suspicion, which I confirmed with a blinded experiment: I sat for 30 min with my back to a wireless router while a friend turned on the router at a time unknown to me. I was able to identify that moment when, less than a minute after, I developed a splitting headache. It was then clear: radiofrequency radiation (RFR) was the primary cause of my health troubles.

With several kinds of meters in hand, I soon learned that measurable EMFs can be found almost everywhere—be it low-frequency electricity in wall sockets, wiring, and appliances, or highfrequency RFR used by Wi-Fi systems, cordless phones, cell phones, cell towers, and some appliances. Each person with EHS has a unique pattern of symptoms caused by different types of EMF; for me it was solely central nervous system symptoms caused more by RFR than lower-frequency EMF. After months of meticulously monitoring my environment with EMF meters and careful journaling about the resulting symptoms, I was able to tease out my typical reaction to an RFR exposure: A buzzing headache and mental slowing starts within 2 hr of an exposure, peaks at 4-6 hr, and lingers for 24-48 hr.

For months after the onset of severe symptoms, I continued to get exposed several times a week, which meant my brain was being reinjured repeatedly and I felt sick almost all the time. Making matters worse, I was now seriously sensitive to something found almost everywhere in my environment. My entire world felt unsafe.

I became, in a word, *overwhelmed*:

- Intellectual overwhelm: How can I begin to learn all that I need to know?
- Physical overwhelm: How can I work to improve this situation when I feel terrible all the time?
- Financial overwhelm: Will I lose my job? If so, how can I pay for all the interventions that might help?
- Emotional overwhelm: Is excess anxiety part of an EHS-induced hyperactive nervous system or a result of all this overwhelm?
- Relational overwhelm: Do my friends and family think I'm crazy? Whom can I turn to for help?
- Spiritual overwhelm: Why me? Where is safety? Will "sanctuary" ever again be possible?

The underworld journey had begun.

The usual pattern is, first, of a break away or departure from the local social order and context; next, a long, deep retreat inward and backward, as it were, in time, and inward, deep into the psyche; a chaotic series of encounters there, darkly terrifying experiences, and presently (if the victim is fortunate) encounters of a centering kind, fulfilling, harmonizing, giving new courage; and then finally, in such fortunate cases, a return journey of rebirth to life.—Joseph Campbell (1972, p. 208)

¹There is a long history of "the underworld journey" being an important mythological motif (the descents of Inanna and Persephone), a common literary theme (beginning with Homer's Odyssey, then Dante's Inferno, and beyond), a central archetype in modern depth psychology (Jung's own inner exploration documented in his Red Book has been referred to as "an underworld journey"), and a mainstream idea popularized by the work of Joseph Campbell (see quotation later in this text).

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The First Ordeal: Fear

Any serious threat naturally prompts a fear response, essential for surviving as a species or as an individual. As almost everyone knows, a fear response usually takes one of three forms:

- Fight: resisting, challenging, attacking.
- Flight: retreating, avoiding, isolating.
- Freeze: immobility, disappearing, helplessness.

Most any of these responses may be reasonable and appropriate during a single attack. But a near-constant threat, like with EHS, can distort and perpetuate any of these into a chronic, disabling state: a variant of a post-traumatic stress disorder.

Faced with real and present danger, each person usually has a goto fear response; fighting back had been mine for most of my adult life. Lost in this underworld, though, I was too overwhelmed—too brain damaged—to do anything but struggle for mere survival. All outside battles were beyond me. My usual response quickly changed from fight to flight: retreating, avoiding, isolating. EMF avoidance can be a healthy version of a flight response for someone with EHS, but in the first year of my illness, this fleeing of mine often degenerated into excessive retreating and isolating—anything to keep myself safe and to settle the fear inside. This extreme withdrawal, however, often led to boredom, disconnection, and a terrible feeling that my life was imploding.

How then was I to transform fear into an ally?

Healthy fear is about self-protection. *How can I keep myself safe? What planning can I do in advance of when I might be threatened?* These questions lie at the heart of a healthy fight, flight, or freeze response: one that will support healing rather than undermine it. Gradually I found new healthier ways to cope with the constant threat of RFR exposure.

- Fight: setting a strong, clear boundary. "Please don't do that."
- Flight: recognizing when a situation is unsafe. "I think I need to leave now."
- Freeze: paying close attention to what's happening around you.
 "This doesn't feel safe—what do I do now?"

Learning to access these healthier versions of a fear response took me several years. First came lots of self-education, then increasingly meticulous shielding and avoidance. These helped to reestablish a sense of safety, which then allowed fear, and occasional panicking, to settle down.

Slowly fear morphed into an ever-awake ally, scanning my environment and guiding self-protective action. I renamed this ally "mindfulness."

The Ordeal of Shame

Fear was the dominant emotion during the earliest days in the EHS underworld, prompting me to retreat so radically that I had little concern about what others might think. As I started re-engaging with others, what they were thinking began to worry me more. Shame soon became even more troublesome than fear, with concerns about what others were thinking often overwhelming fear of physical harm. Instead of protecting myself, I would say and/or do nothing. Repeatedly I suffered exposures and further harm to my brain, all in the name of "looking good."

Why did I let this happen?

Shame first takes shape in preconceptions about what it means to look good, to fit in, to be accepted. Consider all the ways I no longer "measured up." I was brain-injured. I was at serious risk of losing my job. I had an illness that few knew anything about and many health care professionals didn't believe was real. I had to take strange precautions to protect myself. I had to isolate myself so much that I could no longer carry on conversations about the latest movies, parties, and events. Each and every one of these "failings" (and more not mentioned) was an assault on my self-image, regardless of what others were thinking.

But what are they thinking and saying?! This is how shame, like a nasty worm, would burrow deeper into the limbic system of my brain.

During years of doing hospice work, I have seen repeatedly how people react to others with a serious illness: Some are inspired to move in closer and help, while others scatter. When a health issue is not well known, like EHS, the discomfort felt by others can be accentuated even more. Common responses, all designed to create emotional distance, may include the following:

- Confusion: "I don't get this. Is your illness even real?"
- Disbelieving: "It's all in your head."
- Blaming: "You caused this yourself."
- Revulsion: "Yikes, look at you!"

Shame had burrowed so deeply into my psyche that avoiding these responses was often more important than protecting myself.

A psychiatrist-friend offered me insight that helped change this.

According to my friend, shame seldom has a positive value. In contrast, guilt—a close relative of shame—can serve an important role when a person has harmed another; going forward, appropriate guilt and remorse can help make that perpetrator a better partner or friend. But what about people who feel ashamed for something that isn't their fault? Is there any redeeming value to shame when a person has a serious chronic illness that leaves him or her disabled, disfigured, or unable to interact in a normal manner? Her answer was a simple no.

But with deep healing, my friend went on to say, shame can turn into humility. Shame, she helped me see, is a dark tangle of vanity, self-blame, embarrassment, and self-criticism. Humility isn't about $\ensuremath{\mathfrak{D}}$ any of these. Humility is a blend of understanding, self-compassion.

self-respect, and dignity—a bowing down to something bigger, begyond one's control.

And so I began asking myself: *How can this moment of shame be an invitation to be humble?* This practice—maintained over many an invitation to be humble? This practice—maintained over many months—slowly helped untangle the internal mess of shame. In time, ightharpoonup I was able to say to myself: This is who I am. No shame, no blame. Take me as I am.

Shame, to my surprise \exists I renamed it "humility." Shame, to my surprise, soon became a friend-even a trusted ally.

Entry The Next Challenge: What Is Sanctuary? aWhere Is Home?

Talking about transforming fear and shame is getting ahead of the story. As long as I was still deep in the underworld–feeling forever gunsafe and seeing no way out—fear and shame were inevitable. Early on, it was all I could do to name these core emotions for what they were, trying to prevent them from dominating while learning how best to Eprotect and heal myself. If and when I found some degree of sanctuary, then transforming these difficult emotions might become possible.

But not until then.

247.21 Abraham Maslow (1954) is well known for his hierarchy of human needs, the most basic being physiological needs then followed by $\frac{5}{2}$ needs, the most basic being physiological needs then followed by safety needs. Maslow describes the second tier of safety needs as including "security; stability, dependency; protection; freedom from fear, from anxiety and chaos" (p. 39). In other words, what humans need most—after air, food, and water—is some kind of sanctuary. Only when both physiologic needs and safety needs are met does it become possible to thrive, and perhaps to self-actualize.

It's easy to understand how a war-ravished community will have these basic needs disrupted, even obliterated, forcing many to be-

come refugees in search of sanctuary. But what if the assault comes from something that, just in the last decade, has become allpervasive? And what if that something can't be seen, heard, smelled, tasted, or felt... unless you are acutely sensitive and it makes you seriously ill? At once, you risk becoming a refugee and you risk being considered crazy by those from whom you might otherwise have asked for help, perhaps even for asylum.

Soon after my descent into the underworld of EHS, I faced a monumental decision: Should I become a refugee, moving out of my home of 25 years in search of an EMF-free sanctuary? Or, nearing the age of 60, should I take my last stand in this house? I decided to stay.

Why? Because where I lived was much more than just a house-it was "home."

"Home" can mean so many things. Safety and sanctity. Family and familiarity. Continuity and comfort. Conversations and camaraderie. A garden out back and a garden inside me. Most importantly, the place where I had lived for so long held many memories; those memories created the stories I told about myself, and those stories were deeply intertwined with my identity. A home of 25 years was not to be tossed aside on impulse-however desperate I might have been.

The second reason for staying in this house was simpler: Because I could.

Unlike some who are newly afflicted with EHS, I was blessed by both having a home and by the good fortune that the nearest cell towers were a mile away. And unlike some with EHS, I was blessed with having a director at work who was willing to accommodate my situation, which meant I would still have the financial resources needed to make this final stand. Room by room, the house was rewired, and the walls and windows were covered with RFR shielding materials (on the walls metallic paint and on the windows silvermesh curtains, aluminum screening, or special window film). Within a year, I had the low-EMF sanctuary that I so desperately needed. But that meant more than just having a sanctuary. I still had "home."

Another Ally: Sanctuary in the Natural World

The reclamation of my home was a huge relief. However, I also had lost freedom of movement throughout my hometown. I couldn't go to stores, cafés, restaurants, or theaters. I couldn't even go for a walk down most streets or visit my friends' homes. Living most of one's life in a single building, I learned, leads to terrible claustrophobia. As I said before: isolation, boredom, disconnection, implosion.

I was saved from the worst of this by yet another blessing: my wilderness work. Once every few months, I would escape to an EMF-free place in the natural world. On one particular trip—a 4-day solitary retreat in the Mojave backcountry—I was taught two transformative lessons by that unsullied land.

The first: The problem I was facing wasn't located inside my body but outside in an EMF-polluted environment. This health challenge wasn't "my fault." That single insight, more than any other, made possible the transformation of shame into humility.

The second: Sanctuary in the world, outside the bunker of my home, was possible. Among this Mojave wonderland of rocks, I could walk freely. No buildings. No EMF meters. No protective clothing. No fear. No shame.

These were two major revelations—two important signposts during an ascent out of the underworld.

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The Koan of a Glass Half Empty

People afflicted with a life-altering chronic illness, like EHS, are faced with a classic "glass half empty or half full" koan. Do they become embittered, even enraged, by all that they've lost? Or can they reclaim a joyful view of life, in spite of their maladies? The key—I've come to see firsthand—is learning again how to be grateful for whatever life's blessings still remain. This has been one of the great gifts that I found in the underworld, along with reclaiming a home sanctuary and the return of reasonable health.

Before my trip to the Mojave Desert, I found a book, *Living in Gratitude*, in which Angeles Arrien (2011) describes four portals of gratitude: different ways that we can be thankful for what life brings. Each day of that 4-day wilderness retreat, I entered one of these portals to explore the various ways I was still blessed to be in this world.

- Protections: All the ways that I had learned to protect myself were huge gifts. During the first few years with EHS, these interventions were the most important reasons to be grateful.
- Mercies: Opening the heart was so important in those early years. At first, I desperately needed the gift of compassion from friends and coworkers. Later, after I had recovered some, I was equally blessed to regain the capacity to have compassion for others.
- Learnings: Hundreds of pages of journaling were one long testimonial to all I learned about EHS. Every insight was a reason to be grateful.
- Blessings: Sometimes an unexpected blessing would happen. These moments have been special gifts, making life easier or more joyful—each a reason to be thankful.

These four portals of gratitude, I came to see, are where the light comes streaming into my life (into any life, really). Letting in this light—noticing it, allowing it to land, feeling its warmth—has become a regular practice. Now, a few years out of the underworld, I've come to believe that the glass of my life isn't merely half full, but—in all that matters to me most—it is filled to the brim.

Labor and Rebirth

My underworld descent began in 2013, and the return to the light of day came in 2014. Now as I write, in 2017, rebirth into the world seems complete. Meticulous shielding and avoidance reduced the major RFR exposures in the past year to fewer than 10. With that, my brain has healed enough that I now have nearly as much mental energy, creative inspiration, and joie de vivre as I've ever known. And

yet I am still as hypersensitive as ever (each major exposure in the last year had me feeling ill for 24+ hours), so my freedom of mobility remains seriously restricted.

Finding a place in the world remains hugely challenging, and crucial for this has been reclaiming my capacity to fight, instead of always fleeing. Early on, as mentioned earlier, I lost my ability to fight—the only exception being times that I lashed out, like a caged animal, when people violated my sanctuary space. These outbursts, though, were more panic reactions than conscious self-assertions. In contrast, rediscovering a healthy anger response has been a revelation, like the return of an old friend, someone I once had known well but had long forgotten. With access to a healthy version of anger, I was again able to assert myself: "No—no thank you" or "No—please don't do that." This kind of well-channeled anger can be a source of personal power—essential for setting boundaries, for righting an injustice, for helping transform a difficult situation.

And then there are those times when a person just gets *ANGRY!*Back in my early 30s, while I was traveling in Europe, I found myself at dinner with an American businessman in his 60s. I remember nothing from that encounter save for his one great wisdom, passed from age to youth. "In a work setting," he told me, "it's important to get angry about once a year—no more, no less. Get angry too often, and people avoid you. Never get angry, and you risk being dismissed, ignored, or mistreated."

The older I get, the more I wonder if the open expression of anger is *ever* necessary. I do think it's possible to display personal power—to be seen, respected, and not dismissed—without a yearly outburst. But I'm still finding my way with anger, my old friend—learning again how to wield this volatile energy. As I do, this inner force is helping me set boundaries, reclaim my self-respect, and take my place in the world.

Anger, too, has become a trusted ally. I renamed it "healthy self-assertion."

Clarion Call from a Canary

In 1979, a Japanese company was the first to provide cell phones to consumers. In the decades since, each new generation of cell towers and cell phones has brought another quantum leap in data transmission and, with that, an increase in RFR in most communities. The American public has accepted this with an enthusiasm reminiscent of cigarette smoking during the first half of the last century—a time when no precautions were being taken for something that had serious health risks.

Unfortunately, American policy runs contrary to *the precautionary principle* found in public health. This principle says that when an

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action or policy has a potential for harming the public or the environment, and no clear professional consensus exists, then the burden of proof about its safety rests with anyone initiating such an action or policy. European laws include elements of this precautionary principle, while American laws do not. Obstacles to the United States taking a precautionary approach with RFR technologies are several: The potentially offensive agent is invisible, silent, odorless, and often addictive; the general public is minimally informed about possible health risks; and the telecommunications industry is a powerful lobbyist. As I have written elsewhere (Eberle, 2014): "Definitive future research will likely confirm or deny suspected dangers. In the meantime, we are conducting a large-scale, uncontrolled public health experiment that may have dire consequences for many people" (p. 29).

Meanwhile, a person with EHS is the classic *canary in a coal mine*, calling into question how safe the general public is. Yet denial about the public's risk is supported by disbelieving professionals and nonprofessionals alike, who dismiss EHS as being "psychosomatic," "idiopathic," or the result of "an overvalued idea." This dismissal is fostered, in part, by the invisibility of physical symptoms suffered by an electrosensitive person. When healthy people encounter someone with EHS, all they may see are "odd behaviors" triggered by overwhelm, fear, anxiety, and shame.

While the search for measurable biomarkers by Johansson, Blank, and Belpomme helps confirm that this sensitivity is real, even this approach suggests that the illness is located only inside the sick bodies of hypersensitive people. More accurately, the maladies of EHS and CS originate not in hypersensitive bodies but in our polluted environment. One might even say it's our degraded environment that is "sick," and those with ES, while also injured, are the ones who make that environmental illness apparent to all.

I close by underscoring the social justice dimensions of being afflicted with an environmental sensitivity. As was said, overwhelm

I close by underscoring the social justice dimensions of being afflicted with an environmental sensitivity. As was said, overwhelm takes many forms—intellectual, physical, financial, emotional, relational, and spiritual and therefore the resources needed to recover from EHS need to be just as varied. Many people with EHS do not have all of the same resources that I've had. Imagine if a severe hypersensitivity were to manifest in someone more marginalized than a privileged White, upper-middle-class physician like myself. What if this were to happen to a Black, inner-city woman already prone to anxiety? Or a White male laborer with a history of depression who lives in a small town directly below a cell tower? Our

collective societal response to environmental degradation—or lack thereof—will greatly impact how quickly a more vulnerable "canary" dies off.

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