The Distressed Body

Rethinking Illness, Imprisonment, and Healing

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For Janice McLane, my wife, fellow-philosopher, and best friend

Rethinking Pain: The Paradoxical Problem

Chapter 1 introduced the experience of illness with a literary example. Poets and dramatists often probe more deeply into the human predicament than do academicians. At the same time, there is merit to a more formal, structural exploration of experience. In this case I will not try to take on "illness" in its totality. The first chapter made some provisional generalities. Yet there are so many different kinds of diseases and injuries, each invoking its own special modes of distress and disability, as well as different individuals experiencing them in unique ways, that it would be an indefinitely large project to explore illness in all its forms. One can imagine a series of textbooks, not simply of diseases—diabetes, rheumatoid arthritis, chronic ulcerative colitis—but of illnesses, that is, of the experiential correlates that often accompany each of these syndromes.

In this chapter I will narrow my theme to that of physical pain. It is both particular in nature, yet wide-ranging in its manifestation across a range of injuries and diseases (and life in general). I specify *physical* pain to distinguish it from other modes of psychological, existential, and social suffering—grief, depression, and the like. Yet I will also call into question the very distinction just invoked. "Physical" pain is an experience, and one in which grief, depression, isolation can provide its very texture and intensity.

I will also focus primarily on *chronic* physical pain, rather than brief, acute, and perhaps medically resolvable pain. However, again, this distinction is ambiguous. "Chronic pain," which can feel quite acute, is defined by different sources as pain lasting more than twelve weeks, six months, or a year. It can also be understood as pain that no longer has a clear etiology or telos, but "persists after all possible healing has occurred, or, at least long after pain can serve anv useful function." But while both medically and experientially imprecise,

the notion of "chronic pain" does capture something—a pain that persists, and persistently raises questions such as "what is going on here?," "will this ever end?," and "why me?".

Instead of employing a literary account, like that supplied by Sophocles, I will use a personal example concerning a recent and ongoing pain experience. This taken by itself would be methodologically questionable given the idiosyncrasies of any individual case. The numbers of people suffering from some form of chronic pain is huge—according to the Institute of Medicine in the United States, about 100 million adults.² There is also an extensive literature on pain—philosophical, clinical, and sociological—utilizing and supplemented by many individual "pathographies" written by those grappling with serious illness. I will draw on that substantial literature. Yet using the method of phenomenology—the careful examination of the structures of experience, having "bracketed" (set aside) any precommitments to metaphysical or scientific-causal structures of explanation3—there is something to be gained through reflecting on one's own experience. We have seen that pain, immediately present to the sufferer, is difficult to objectify and communicate. I will supplement my reading of others' descriptions with what persistent pain has felt like from within, speaking about it as best I can.

The methodological ambiguities mentioned above—pain as physical/psychological, chronic yet acute, accessible in different third-person/first-person ways—I take to be ingredient in the topic itself. In fact, such ambiguities *are* the topic. Pain, I will suggest, and especially persistent pain, involves negotiating a series of dialectical tensions and experiential paradoxes. These can be the source of doubt, struggle, frustration, and confusion that greatly add to the painfulness of pain. In this chapter I will examine no less than *nine paradoxes* associated with fundamental questions that arise for the person in distress. In such a way I will take off from, but deepen the analysis originally triggered by Philoctetes' painful wound.

1. Sensation and Interpretation

First, what is this pain? In a certain way, the answer to this question is clear—this is the pain, this immediate, unpleasant, somewhat inexpressible, sensation. Elaine Scarry, in her influential *The Body in Pain*, characterizes it as a unique bodily experience. Senses such as hearing and sight apprehend objects. Even intentional states such as hunger or fear remain "hunger for" or "fear of" something. But she writes "pain is not 'of' or 'for' anything—it is itself alone. This objectlessness, the complete absence of referential content, almost prevents it from being rendered in language." Hence, we can be reduced to grunts

and cries like Philoctetes. Only subsequently, and often analogically, does pain come to be connected with objects in the world.

There is a phenomenological truth here—pain can suddenly seize us from within, collapsing our complex world of involvements. Still, I would challenge Scarry's characterization of pain as nonreferential.

My own pain was consistently a "pain of." As the content of what it was "of" shifted, so too the experience. Consulting orthopedists about a lower leg pain, and then vascular surgeons, neurologists, a pain specialist, an acupuncturist, and a plastic surgeon—along with my own, sometimes obsessive, skimming of webpages-led me to many different answers concerning what this was a "pain of." With each new interpretive perspective, the sensed pain itself changed in quality, intensity, meaning, and affective content. The pain of a possible stress fracture felt sharp, as if something inside was indeed broken. When viewed as ankle "inflammation," it exuded warmth. When varicose veins seemed the cause, I felt a heaviness in my leg. The ultimate diagnosis of a "peripheral neuropathy" highlighted the pain's stinging and burning qualities. Also, based on the shifting prognoses, these pains felt at times more serious or less so, on the way to recovery or depressingly untreatable. Each different pain also cried out for a different response. You do not, for example, walk on a stress fracture. My leg pain then seemed to be telling me in no uncertain terms to rest. But when the diagnosis shifted to a focus on varicose veins (where exercise is important to keep blood from pooling), my pain now felt like a call to get up and move.

Pain thus partakes both in the immediacy of sensation and the mediacy of complex referentiality and interpretation.⁵ We realize this as well through biological reasoning. Pain serves as a protective mechanism whereby a living creature is made aware of actual or potential tissue damage and is motivated by the aversive quality of the sensation to take corrective action.⁶ As such, pain calls for creatures to feel, investigate, respond. Wall, a neuroscientist and pain expert, writes, "I have never felt a pure pain. Pain for me arrives as a complete package. A particular pain is at the same time painful, miserable, disturbing, and so on. I have never heard a patient speak of pain isolated from its companion affect."

The neuroscientific "gate control" theory Wall helped introduce also suggests that pain experience is not simply the result of a peripheral stimulus but is filtered and modulated by spinal and cerebral centers of the central nervous system. This theory, "with its emphasis on parallel processing systems, provided the conceptual framework for integration of the sensory, affective and cognitive dimensions of pain." I will not dwell further on such scientific theories. They are suggestive but also likely to change as research continues,

and in any case, should be "bracketed" from a phenomenological perspective, such that second-order explanatory accounts not displace our investigation of "the things themselves."

In the first chapter I contrasted "illness" (experiential) with "disease" (medical category). Yet I have said that this division is provisional. Scientific interpretations sink into and vector our life-world. Pain experience can oscillate between the pole Scarry emphasizes—that of nonreferential sensation—the pure "ouch!"—to that of complex interpretation, as when the doctor tells you this "ouch" may be a sign of diabetic neuropathy. The "ouch" can even be created out of the diagnosis. Groopman, himself an expert oncologist, describes an occasion where a bone scan he underwent for a hand problem revealed what seemed to be metastatic cancer in his ribs. "I generally think of myself as reasonably well put together psychologically, but within moments my chest began to ache. When I touched my ribs, they hurt." Further tests revealed no such cancer, but it took several hours for the ache and tenderness to subside.9

Diagnosis changes our sensations. New sensations can also change our diagnostic picture. Chronic sufferers who repeatedly survey and evaluate their pain, in dialogue with the medical community, may find themselves in a hermeneutical circle that has no clear terminus. ¹⁰ Chapters 6 and 7 will examine in more depth the complex hermeneutics of diagnosis and the way it arises from and impacts the treater-patient relation.

2. Certainty and Uncertainty

This all leads us to a second paradox of pain: that between certainty and uncertainty. Again, Scarry provides a way into the topic, though one I will again challenge. She writes:

Pain enters into our midst as at once something that cannot be denied and something that cannot be confirmed (thus it comes to be cited in philosophic discourse as an example of conviction, or alternatively as an example of skepticism). To have pain is to have *certainty*; to hear about pain is to have *doubt*.¹¹

Scarry is surely right about this existential/epistemological split dividing the sufferer from others. Though my family never actively doubted my complaints—in this I was fortunate because there are skeptical families, employers, doctors, and government officials—they couldn't know it from within as I did. I either kept quiet (which increased my sense of isolation) or tried to convey my pain through groans and words (which made me feel like a complainer). In either case, though they behaved with compassion, I remained experientially on my own. That is, I dwelled on Philoctetes' island. This was

true as well in my relationship with doctors, including the many who were kindly. My suffering, so searingly present for me, was to them an interesting puzzle—until it proved insolvable by or irrelevant to their particular discipline, in which case their interest might wane.

But is Scarry right to assert that "to have pain is to have *certainty*"? True, one has privileged and indubitable access to one's own mental states. This was at the core of René Descartes's *cogito ergo sum* realization. Clinically, one can and should respect the patient's self-report. Yet I would contend that there are features of radical *uncertainty* for the experiencer of pain, not only for the one hearing about it. I found my own pain states often opaque and ambiguous in any number of ways.

"On a 1–10 scale how would you rate the intensity of your pain?" This common doctor's office question can lead to bafflement. My pain would shift moment to moment or at different times of day. And at any time how intense is it really? Am I being a big baby, exaggerating a minor ache, or am I someone with high pain tolerance (something I was once told), soldiering on in the face of a major assault? Is it *really* a 3 . . . or a 6?

And where is this pain exactly? There were surface stings and stabbings, along with burns and deep aches difficult to locate in the nether-space of the bodily interior. This was like the coenesthetic equivalent of seeing a shadow move, uncertain whether it was a menacing stranger or simply curtains waving in the wind. The pain can take on an uncertain and therefore uncanny nature—what did I just feel? Neither friend, doctor, nor technological device can step in to answer that question.

Hence, the radical doubt that Scarry refers to is not simply the property of the "other" but can also permeate the world of the sufferer. Even the absence of pain is open to question once chronic pain has become the norm. "I don't remember being in pain this afternoon," I would think to myself. "Maybe my ankle is finally healing. But I was busy teaching class. Was I really not in pain or just too distracted to notice it? But if I didn't notice it, was it still pain?" This is a version of the old question, "if a tree falls in the forest but no one hears it, did it make a sound?" but now referring to one's own unclear, interior forest.

3. Present and Projective

An associated question arises: "When is this pain?" Here I do not refer to calendar time—one can often know with great precision, as I did, what day pain first appeared or when in the evening it worsens. But this sidesteps the issue of what pain does to time-consciousness itself—the "when" of it in this sense.

This is a complex and multidimensional issue, which I have not the time—paradox intended—to treat fully in this chapter. But, returning to the literary world, here a poet such as Emily Dickinson, famous for her own brevity, may get us started:

Pain—has an Element of Blank— It cannot recollect When it began—or if there were A time when it was not—

It has no Future—but itself— Its Infinite contain Its Past—enlightened to perceive New Periods—of Pain.¹²

Dickinson articulates an alteration of normal time-consciousness. Though she refers to past and future—the projective "ecstases" of time, to use Heidegger's term¹³—the "now" of pain is never explicitly mentioned. Yet this is because present pain is everything, has swallowed up the world, until it "cannot recollect... A time when it was not" and "has no Future—but itself."

When pain is severe or persistent, it can feel like this. It is very difficult, though perhaps not impossible, to project beyond it—that is, to use one's powers of recollection, imagination, positive anticipation to escape its grasp. Physical pain—in my case, specific nerve shocks and spasms—kept seizing me back to the here and now. This lived present may also slow and expand. In Brough's words, "Thus the now of the pain I live through may appear to me to be endless, while the procedure inflicting it may by the clock take only 45 seconds." Concurrently, for the person in pain, "Hopes, dreams, and aspirations for the future might seem to disappear, stranding the person in the unsatisfactory present." In my case, this led me to the edge of desperation, from the Latin *desperatus*, meaning "without hope." Even making one's way through a single painful evening—until the clock renders permission to call it bedtime—can be like slowly swimming through a thick tide, time itself a resistant medium.

This immersive present need not always be so negative. Forced by my painful ankle to slow down, sit down, and eventually to calm down, I have done deeper reading and contemplation than I would otherwise. Ironically, I've been working my way through Marcel Proust's multivolume *In Search of Lost Time*, a work I set aside some twenty years ago. I just didn't have the time then—but do now, thanks to the way my injury slowed and emptied time.

It can also be healing, particularly when facing an illness with an uncertain, or even fatal prognesis to choose to remain femiliar and the state of the state of

Carel writes, "Focusing on present abilities, joys and experiences instead of worrying about a no-longer-existing past and a not-yet-existing future, is a way of avoiding some of the suffering caused by illness." ¹⁶

True, but chronic pain can also poison the "now" with suffering. Rather than returning to the present as a joyful home, it may appear quite "unhome-like." With no clear end in sight, time's briefest slice can expand into Dickinson's harsh "infinite," a prison sentence of indefinite length. Pain thus motivates a variety of attempts at jail break. That is, its felt aversiveness not only fixes us to the present but compels us to run away. We project outward to other time realms in search of relief. Some might turn to comforting memories. A life review can recall happier times and place the pain episode in broad perspective.

In my case, I turned my attention more to the future. When will I find a proper diagnosis and treatment? When is the appointment with the next specialist? When will this pain go away and real life recommence? On such questions I focused with the intensity of a dog staring fixedly at his master's hand, hoping it holds a treat, yet afraid of a beating. This search for a pain-free future can be freeing (there is hope) but also limiting and solipsistic. "The focus becomes entirely directed on the self. All purpose becomes directed at the relief of pain, sickness and suffering." 18

The temporality of pain thus unfolds in paradoxical tensions—the "now" both summons and repulses; the past can comfort but ever recedes from our reclamation; the future opens up horizons of possibility, but it can neither satisfy our higher aspirations nor provide certainty of relief, and may in fact threaten a worsening of symptoms.

4. Never-Changing and the Ever-Changing

Chronic pain introduces another temporal paradox: it can seem simultaneously both never- and ever-changing. The term "chronic" from the Greek word for time, *khronos*, suggests that certain modes of suffering are set off, made different, by the long passage of time. Again, this is not just the calendar times—three months, six months—referred to by clinical definitions. To the sufferer, chronic pain can seem to go on and on repetitively, like a nightmarish version of Friedrich Nietzsche's eternal recurrence. ¹⁹ To reawaken each morning to the same constricting pain, no matter how freely one moved in one's dreams; to know that it gathers intensity each evening starting around 7 p.m.; to find that after a certain amount one can walk no more because the pain has arrived to enforce its restrictions; to survey hours, days, weeks, months, and be unable to discern demonstrable improvement: this is to feel oneself trapped in

a never-changing time. In Dickinson's words, "It has no Future—but itself— / Its Infinite contain . . . / New Periods—of Pain."

Yet, and paradoxically, this "never-changing" pain is constantly fluctuating. As the above examples suggest, pain can alter according to time of day, exercise, body position, a texture that brushes up against the skin, even a passing thought or mood. In longer terms, one's condition may be improving or degenerating according to the specific nature of the illness and treatment, which impose their own temporal progressions.

At times, pain may entirely disappear. The experience then of *not-being-in-pain* differs from the pain-free state that is taken for granted when one is healthy and therefore rarely thematized. This *not-being-in-pain* is noticeable, perhaps startling, inducing both hope and fear given its precarious nature.

I found, though, that what Dickinson says about the temporality of pain works equally well when inverted:

Not-Being-in-Pain—has an Element of Blank— It cannot recollect When it began—or if there were A time when it was not—

That is, when my leg pain went away, in my blessed relief I had difficulty reconnecting with past experiences of pain (even if I retained an intellectual memory thereof). Pain is such an intense *presence* that when it disappears for a time it can simply feel *gone*. This actually proved problematic for me because those better times would lead me to incautiously overdo my walking and climbing, no doubt hastening the return of serious pain. Amnesia concerning past agonies was associated with deficient anticipations concerning the future—I lacked clarity that pain could and would return, especially if I wasn't careful.

Thus chronic pain can oscillate in ever-changing patterns. It is boring and unremitting, yet also endlessly novel in its play of forms. The author Alphonse Daudet (a close friend of Proust), when dying of tertiary syphilis, wrote, "Pain is always new to the sufferer, but loses its originality for those around him. Everyone will get used to it except me." This ever-newness can trigger "the start of an obsessive process of self-observation in our painful bodies" that further isolates us from others and from life's richness.

More positively, moment-to-moment awareness of shifting sensations can also yield beneficial results. What Carl Jung said of life and the process of aging is also true of even a day spent in pain: "But we cannot live the afternoon of life according to the programme of life's morning; for what was great in the morning will be little at evening, and what in the morning was true will

at evening have become a lie."²² I found literally that what in the morning might lessen my pain (for example, exercise) might in the evening increase it. Akin to Buddhist mindfulness practice, I learned to listen carefully for the body's changing messages and the shifting strategies that might best serve each moment.

Yet this dialectic of the "ever-changing" and the "never-changing" dimensions of chronic pain can lead to (very un-Buddhist-like) cycles of hope and bitter discouragement, and sometimes the sense of doing much but accomplishing nothing. Then "chronic pain" is truly the pain of time itself (*khronos*), unless and until the sufferer can make peace with this three-faced god of past, present, and future.

5. Mind and Body

I have been discussing the "when" of pain—its temporal profile. But *where* does the pain unfold? At least within our culture, steeped in a dualistic religious and philosophical heritage, two options immediately present themselves: it is in my body or mind. Paradoxically, both seem experientially confirmable.

It is clear, in one sense, where my ankle pain is located—in my ankle. I can reach down and touch the site of pain. This injured body seems largely recalcitrant to my mental intentions and desires. Yet when I probe experience more deeply, as Descartes did in his famous meditations, I can also arrive at a seemingly opposite conclusion: pains are actually in the mind, events (or "qualia," to use contemporary philosophical language) that present themselves within my stream of consciousness. Such may be triggered by physical forces—for example, tissue or movement compressing my saphenous nerve—but the pain itself, the aching and burning, is an object of conscious experience.

These two perspectives on the "where" of pain tend to re-present themselves in the causal analyses and treatment options available to the pain patient. As Kleinman et al. write:

The medical literature privileges objective somatic processes, and it enshrines them as the agent that produces pain. The psychological literature takes the opposite position: it imputes agency to the subjective mind (as affected by specific behavioral contingencies and family dynamics); these mindful processes then produce physical pain. The Cartesian dichotomy remains unquestioned.²³

More holistic understandings try to bridge this Cartesian dichotomy by variously blending, or attending to, both sides. The International Association

for the Study of Pain, for example, defines pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage."²⁴ With both mental and physical components playing a part, pain management guides often recommend multidimensional interventions: medication and meditation both have their uses and often work well in synergy.

However, for the patient in pain, the "mind-body question" may remain a lived, perhaps irresolvable, paradox. Good records an interview with a young man, Brian, who has long suffered from intense pains in his head, throat, and ears. Temporomandibular Joint Disorder (TMJ) has been offered as a possible physical diagnosis, but Brian remains unsure: "Is it my body? Is it my thinking process that activates physical stresses? Or am I, or is it the other way around? It's all that uncertainty." 25

Many in chronic pain can relate to "that uncertainty." At times, my ankle pain seems something mechanically produced by the forces involving in weight-bearing joints, nerve transmission, and the like. There then seems little I can do except stay off my feet. At other times I understand pain more as an object and product of my consciousness, and therefore one that can be modulated by positive reframing, healing imagery, even self-hypnosis. This mentalizing of pain can feel empowering (I can alter my experience) or guilt-producing (the pain is worse today; I must have been thinking wrong thoughts). Physicians have learned, quite rightly, not to label chronic pain syndromes "psychogenic," which tends to be stigmatizing, implying "it's all in your mind." But with the causative factors of chronic pain complex and unclear, what exactly is initiated by mind and what by body may be puzzling for patient and physician alike.

6. Self and Other

Part of the problem may lie in the flawed metaphysics of mind-body dualism. Phenomenologists, such as Merleau-Ponty, have proposed that it is more experientially illuminating to understand the person as a unitary "lived body." We do not just *have* a body, as if it were some object in the world to which our intellect is mysteriously attached. We also *are* our bodies. Our subjectivity, that is, our powers of perception, movement, desire, communication, are all profoundly embodied modes through which we inhabit our surroundings. In short, "The body is our general medium for having a world."²⁸

Yet viewing ourselves in this more unitary fashion does not fully resolve the experiential paradox of where pain is. We may no longer frame this in relation to the mind-body question, but there remains an issue of whether pain is experienced as fundamentally within the self or as other. For the sufferer, the answer may be both.

The healthy body serves as a largely transparent medium through which we explore and act upon the world.²⁹ When striding along the trail, I am free to enjoy the blustery spring day, birdsong, and early leafing trees. Yet my leg injury shifts focus. My attention now folds back upon my own body as a problematic object—how is my leg doing? I wonder, step by uncertain step, noticing with foreboding its twinges.

As such times, the body reveals itself as both an inescapable part of me and an uncanny "alien presence." In Scarry's words, "Even though (pain) occurs within oneself, it is at once identified as 'not oneself,' 'not me,' as something so alien that it must right now be gotten rid of." There are biological benefits associated with such an attitude: objectifying the bodily process enables one to offer it up for study, repair, or even amputation. Yet this is not always easy since the "other" in question is very much a part of me and mine. This, in Slatman's words, is the deep existential "strangeness" of the body: it is both the source of one's identity and powers, and yet also meat, machinelike, weighty, resistant.

The person in chronic pain must negotiate this ambivalent relationship with his or her body, even specific parts. In my case, over time, instead of viewing my damaged nerve as an enemy, I sought to befriend it, ask it what it wanted, thank it for its good service even in challenging periods. I wondered, if it came time, as a last-ditch method of ending the pain, to chemically or surgically lesion the nerve, could I bear to kill my friend? Yet even viewing the painful body-part as friend does not eradicate the sense of duality—of "me" and "it." This merely modulates our complex affiliation.

Friend? We can try to take this attitude. Yet in chronic pain one may wonder whether this body will not only torture but kill me. This is a clear issue for those with degenerative or fatal illnesses. Even in a less dire case, such as my own, a foreshadowing of mortality occurs. "Pain is a harbinger of death," writes Bakan. Its sensory seizure tells us of the vulnerability of the flesh and seems a seed of our demise ever growing from within. My nerve problem affected my foot area, and I remember one day being struck by the metaphor, "I have one foot in the grave." The whole rest of my body longed for activity, adventure, *life*, but that one foot was dragging me down into Hades.

Pain thus initiates a profound and paradoxical double alienation. As interior to the self, unshareable, inexpressible, pain brings about "this absolute split between one's sense of one's own reality and the reality of other persons." Alienated from others, one is also alienated from an embodiment that now surfaces as another other. Our own body opposes our will, can even

pull us prematurely toward death. This double alienation is not necessarily the endpoint of chronic pain.³⁸ For example, I have mentioned my ability to befriend my injured ankle, and have also found others—compassionate family members and professional healers—to help me with that process. Philoctetes found a caring friend in Neoptolemus, and a divine healing. Yet as we saw in chapter 1, pain has the power to dis-integrate one's relation to others, to one's own body—and as we will now explore, to the world as a whole.

7. Here and Everywhere

For another paradox arises in response to the question of "where is the pain?" In most cases, pain has a location, a "here" that one can point at. In my case, there was a small oval area two inches above the left medial malleolus (ankle bone) that formed the epicenter of my suffering. I would even outline this region with a marker before visiting a doctor. Yet insistent pain can also globalize itself throughout our attentional field. As Proust writes, "Is there not such a thing as diffused bodily pain, radiating out into parts outside the affected area, but leaving them and disappearing completely the moment the practitioner lays his finger on the precise spot from which it springs?"³⁹ Proust has himself laid his finger on an interesting point—that pain can have definite location and/or be diffused, a generalized place in which we dwell as when we simply say "I am *in pain*." Both can be true simultaneously, or we can oscillate between these poles of precision and diffusion as in Proust's example.

Since one's world is always experienced with and through the lived body, we find that pain can even overrun fleshly limits and saturate one's environs. To use Heidegger's term, pain can be a kind of "mood" or "attunement" (Stimmung) through which our being-in-the-world is disclosed. In my case, when on the edge of pain, a path I used to stride with ease was now revealed as filled with crevices, rocks, and other potential hazards. The shrieks of nearby children could take on a harsh quality. The world as a whole might feel vaguely menacing; or drained of all color and warmth; or something muffled and far away, as if one dwells on that isolated island of Lemnos. In such ways, the pain in my left ankle could totalize itself. It diffused like a malignant mist throughout the experienced world. Conversely, when my ankle felt better, not only did I feel like a new person—my self-esteem rising, my voice becoming stronger—but the world opened its doors and windows, beckoning me to cheerful adventure.

Thus a full-scale phenomenology of pain (this is but a partial version, honing in on certain paradoxes) leads us far beyond the perimeter of specific sensation. We see how pain reconfigures our sociality, creating zones of isolation,

others of empathic call and response; it severs space into regions of the near and far, those objects and activities that remain accessible, and others withdrawn from reach, given the limitations of function; it causes contractions of spatiality around the sickbed analogous to the way, in relativistic physics, that mass curves space around itself, exerting a gravitational pull difficult to escape. "Chronic" pain (the pain of *khronos*, time) is also the pain of *topos* (place), changing our place in the world. Analogous to Einsteinian physics, the fabric of experiential space-time is multidimensionally warped.

8. In-Control and Out-of-Control

I conclude here with issues concerning the "how" and the "why" of chronic pain. First, a question paramount for the sufferer: *How* do I gain mastery over the pain? Or must it always have mastery over me?

In one sense, as per the discussion above, pain seems quite out of our control. It may continue despite all our attempts at diagnosis and treatment; tests and medications; the alterations of rest, diet, and exercise; even alternative therapies and petitionary prayer. The pain manifests as a foreign agency, one more persistent and powerful than our paltry efforts. Brian, the patient discussed earlier with possible TMJ, says that when his pain comes on, "It seems like there's something very, very terrible happening. I have no control over it, it's ah . . . I really don't have any control over it, although I like to believe I do."⁴² Pain, if anything, has control over us, determining what we can do and must feel. The Latin word *pati*, meaning "to suffer," is the root of the English words "patient" and "passive," suggesting this lack of agency.

However—and here is the paradox—chronic pain can also create a sense of *hyper-agency* in the sufferer. In my case, far from being absolved of responsibility by my injured leg, I had to exert a level of vigilance and decision making on both micro- and macro-scales that I was unaccustomed to during the comparative ease of health. Before, I could heedlessly head out on a two-hour hike—no big deal. Now I had to be careful with each step, making sure I was leaning to the outside of the foot in a way that would minimize pain on impact. I would decide to ice after a short walk and perhaps try a nerve-cream. I had to stop computer work periodically to rest and elevate my leg, decide whether it felt wise to go to a movie at night or to schedule travel to a conference a few months hence. On many occasions, these decisions were seemingly revealed as "good" or "bad" based on the level of pain control I maintained.

There are hazards to overemphasizing this exercise of control. Arthur Frank, a medical sociologist, reflects on his own experience living through a heart attack and then cancer: "In society's view of disease, when the body goes

out of control, the patient is treated as if he has lost control. Being sick thus carries more than a hint of moral failure; I felt that in being ill I was being vaguely irresponsible."⁴³ Doctor and patient can collude to "blame the victim."

Such can serve as a defense mechanism on the part of the clinician. Patients often arrive with an unrealistic fantasy that modern medicine, with all its high-tech diagnostic and therapeutic powers, must be able to fix any problem or at least remove its associated pain. Sadly, that is not always the case. It is painful for doctors, not simply their patients, to be unable to fulfill this fantasy of absolute control.⁴⁴ Frank's illnesses finally taught him that "giving up the idea of control, by either myself or my doctors, made me more content." It probably also took pressure off his physicians.

That said, treaters can do much to help the person who deals with challenging pain. Melzack and Wall write,

The essential ingredient is providing the patient with skills to cope with the pain and anxiety—at the very least, to provide the patient with a sense of control. . . . [W]hen the patients are taught skills to cope with their pain, such as relaxation or distraction strategies, the pain is less severe. 46

It might be said that in discussing such matters, I am wandering from a phenomenological focus on the original pain experience to "second-order" issues of pain management. Yet, as the quote above suggests, such distinctions are far from absolute. In my own case, I found that merely learning a technique that could help diminish pain itself diminished it. That is, the pain came to feel less sinister, severe, and overpowering. Knowing "there is *something* I can do" made a real difference.

I must say that I received little in the way of skills (as opposed to pills) from the clinical "pain expert" I saw. However, in general I did access state-of-the-art medical care, including alternative approaches, provided through excellent insurance coverage supplemented by my own resources. Many are in a far less fortunate position. As Kleinman writes,

The experience of pain in a world without security (in family, job, finances, or neighborhood) is what distinguishes chronic pain among the poor and the oppressed. When one cannot marshal resources, symbolic and instrumental, because they do not exist or one's access to them is obstructed, the very ideal of control becomes untenable.⁴⁷

Achieving greater control over pain is clearly better, and functional and caring social systems, along with well-trained treaters, are crucial to support that goal. We still live in a time and society where many are without reliable access to high-quality health care, significantly augmenting the painfulness of pain.

Yet even in a supportive context, chronic pain can remain paradoxical, ambiguous. The sufferer both feels the lack of agency and a call to hyper-agency, that is, the rigorous monitoring and micromanagement of activity. The "pain control" achieved often remains partial and uncertain. It is not even clear when it is better to assert personal control, give it over to treaters, or let go entirely of the project of control.

9. Productive and Destructive

Implicit in the above discussions is a last question, which can also be the first question for the person in pain: *Why?* That is, why me? Why this? The answers found are as diverse as those asking the questions and may shift over time for each individual. Yet again we can discern a paradoxical antinomy as pain acts to both generate and destroy the many responses.

We find this ingredient in even a brief pain experience. In the middle of an ordinary day, bending over to tie a shoelace, one's lower back goes into spasm. Immediately one experiences a destructive and distressing component—the world of outward involvements is disrupted. Yet the pain can also be productive, generating new questions and meanings. What is this about? How do I treat it? How do I prevent it in the future? Hopefully, the messages received are both beneficial and practicable. With proper rest, self-care, exercise, the back problem may resolve—lesson learned, and perhaps one's life has been improved.

Chronic pain is not only quantitatively but qualitatively different in its challenge. As Melzack and Wall write,

Pain, which is normally associated with the search for treatment and optimal conditions for recovery, now becomes intractable. Patients are beset with a sense of helplessness, hopelessness and meaninglessness. The pain becomes evil—it is intolerable and serves no useful function.⁴⁸

Stella Hoff, a biomedical researcher who still suffers severe pain four years after a car accident, elaborates on this theme in an interview:

Suffering is an evil. I mean suffering that has no meaning, that brings nothing good with it. . . . My spirit is hurt, wounded. There is no transcendence. I have found no creativity, no meaning in this . . . this entirely horrible experience. There is no God in it. . . . It shatters all I took for granted and believed in. 49

In this poignant quote, reminiscent of Philoctetes' plight before his *deus* ex machina, we see chronic pain's destructive power, and in two senses. First, pain comes to be associated with a series of negative meanings. It is "evil." It

signifies failure and retribution;⁵⁰ we have seen this in the very etymology of the word "pain" from *poinē*, the Greek word for "punishment." Many chronic pain sufferers have a core conviction they have done something to deserve it. Such an interpretation, even when subconscious, can make it difficult to practice self-care and compassion.

Second, pain is associated not only with negative meanings but with the *meaningless*—in its sheer repetitive aversiveness, its senseless reiterations, chronic pain can destroy all our attempt to find any reason, purpose, or divine plan. In Hoff's words above, this is "suffering that has no meaning, that brings nothing good. . . . It shatters all I took for granted and believed in." Pain can be "world-destroying," overturning that which makes life enjoyable and purposeful. As Frank writes, illness in general can be a source of "narrative wreckage," disrupting the course of our life and the stories we have told about it. ⁵² For the religiously minded, a sense of inexplicable abandonment may follow. In the Gospel of Matthew, the last words of Jesus, nailed so painfully to the cross, are "My God, my God, why hast thou forsaken me?" ⁵³

Thankfully, devastation does not always have the last word. (Jesus's cry is itself a quote from Psalm 22, a verse that ends in celebration of God and his people.) Pain is productive as well as destructive on the level of meaning, and again in two ways.

First, as noted at the beginning of this chapter, pain is a bodily experience that naturally produces interpretation. Health allows for a pleasant obliviousness; not so pain, which provokes a search for its significance and remedy. In chronic pain this search also becomes chronic, ongoing over time, as different meanings arise and are abandoned or layered atop each other. Chronic pain can function like a Zen koan: a question repeated, permitting of no easy resolution but therefore provoking us to penetrate ever further.

Second, some of these meanings so produced are genuinely productive for the individual. In Proust's words, "Griefs, at the moment when they change into ideas, lose some of their power to injure our heart; the transformation itself, even, for an instant, releases suddenly a little joy." Over time, the pain we have experienced can trigger specific insights, or the strengthening of character, or the realization of blessings. (That such positives are sometimes thrust too quickly at the sufferer does not mean they cannot come true.) In my own case, I found myself reexamining old family traumas, letting go of guilt that I might be somatizing through bodily pain. My leg pain also has given me precise messages about modes of stress and exhaustion I need to avoid. Perhaps in this way it can help me forestall future stress-induced system breakdown, even the fatal sort. Unable to stride busily about the world, I feel a permission to slow down—to begin to transition into the wisdom years

of later life. I have experienced the power of family and community as many hands reach out to help. I have become more serious about certain meditative and spiritual practices. I listen more closely to my body. I must.

Yet pain remains "the gift nobody wants." Mixed in with anything sweet, the pain has brought me much that was bitter: feelings of personal failure, prayers that seemed to go unanswered, sincere efforts rebuffed by an unfeeling universe, incompetent practitioners, and an untrustworthy body. Again, this is the paradoxical dialectic of chronic pain. Pain is productive/destructive. These go hand in hand, though one or the other may have the *upper hand* at a given time or for a given person.

Conclusions

There is much that this discussion, of necessity, has omitted. Many paradoxes were introduced but only briefly discussed. Any one of them might merit a fuller treatment on its own. Working with generalities, specifics were glossed over—the specificity of particular types of pain; of different disease and injury processes, each with its own patterns; of cultures that may view and process pain differently; and of individuals, each of whom travels a unique journey.

In focusing on experienced pain, this chapter also said only a little about treatment and healing. One need not attain full physical recovery to heal. Sharing the same root with the words "holy" and "whole," healing can involve developing coping strategies, deepening relationships, discovering positive meaning—that is, reintegrating one's self and world in a way that counteracts pain's more corrosive effects. 56 More will be said on this topic in future chapters, including the next one on the healing powers of touch, and chapter 5 on medical practice as reimagined.

What I have tried to establish here is that chronic pain has a "liminal" structure.⁵⁷ Borrowed from anthropological literature and now used across a variety of fields, the term "liminal" refers to that which is not contained within, and defined by, ordinary situations and structures. Instead it inhabits an in-between state, a kind of nether region characterized by "ambiguity, paradox, a confusion of all the customary categories."⁵⁸

I have catalogued nine ways in which chronic pain is liminal: that is, ambiguous and paradoxical, involving in-between states. Pain manifests as both sensation and interpretation, certain and yet uncertain to the sufferer and others. It unfolds in both a present and projective time, exhibiting a never-changing and yet ever-changing pattern. It is seemingly located simultaneously in body and mind, self and other, the here and everywhere. Presenting as both in-control

and out-of-control, pain unleashes productive and destructive forces in the realm of meaning.

If one is fortunate, the pain finally goes away. But in the face of ongoing pain one can still "heal" such that the tensions above—epistemological, existential, even metaphysical—can to some degree be re-solved or dis-solved. At least their capacity to bewilder, frustrate, disorient, and drain the sufferer diminish. Yet this is no easy accomplishment. Pain is more than an aversive physical sensation. It can trigger a series of experiential paradoxes that shock and destabilize one's world.