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HURTING

YET

*Whole*

RECONCILING BODY AND SPIRIT  
IN CHRONIC PAIN AND ILLNESS



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## A JOURNEY BEGINS



We come into this world blissfully unaware of these fragile, beautiful things we call our bodies. In our mother's womb, we bathe in continuous warmth and nourishment, changing shadows and muffled voices, not knowing where our mothers end and where we begin. We are one. We are whole.

Out in the bright, chilly world, most of us pass through childhood in a similar ignorance of unmediated bodily immediacy.<sup>1</sup> We reach out to touch, smell, and taste all the blankets, fingers, dirt clods, oranges, chair legs, and windblown leaves we encounter. Our bodies move and grow, and sometimes get hurt and heal, without our thinking much about it.

Many of us also enter adulthood thinking very little about our bodies. They are just . . . there. They may alert us of their presence if we stub our toe on the bed frame in a nighttime bathroom expedition or when the powdery yellow coat of spring pollen irritates our sinuses. Mainly, though, bodies are the taken-for-granted backdrop to all we do in life. Our feet walk us through the grocery store, our fingers and eyes facilitate our internet browsing, our noses and skin take in the presence of our loved ones. But we don't notice our bodies in

these moments. They just do what they're supposed to do. And we go on living.

Then there comes a time when our bodies stop doing what they're supposed to. They leap from their benign presence in the background and scream for attention. We can't help but notice. We ache. We double over. We can't walk, can't think, can't breathe. Something isn't right. Our bodies fall apart.

For many, this awareness comes with aging. My mother often groans, "I feel like I am getting old." Bodily deterioration—rickety joints, sagging skin, the slowing march of internal organs—is a normal, decades-long part of the business of living that leads to dying that leads to death—the complete halt of bodily function.

For a growing number of us, though, our bodies malfunction long before normal aging sets in. Something goes wrong and refuses to be fixed by one or two visits to the doctor and time. Some of us have joints that start to swell and ache as teenagers. Others have jackhammer headaches that debilitate us for days. Yet others live with fatigue that makes the word *tired* seem like child's play.

For me, it was a niggling pain in my left ankle that spread to my foot, knee, back, and neck. After months of frustrating doctor's visits, varying diagnoses, and ineffective treatments, I just started calling it "chronic pain." Whatever name we end up giving our ailments, whatever treatments we endure, we share the feeling of a sudden disconnect with our bodies. It's not just that we are getting old. "From the moment we are born, we begin to die," the saying goes. When we have a chronic illness, our bodies do not recover the way they should from an injury or change in the internal ecosystem. We don't bounce back. We languish. Our bodies, once friends that came along for the ride,

become our betrayers—all-consuming burdens of pain and frustration that thwart our goals and our chance to live a “normal” life.

### FALLING APART

Before pain, I was invincible. The world was my oyster. I was twenty-two, just out of college, and plotting my globetrotting, book-writing path through God’s green earth. When the pain first started, I didn’t give it much thought. It was some minor sprain, probably, that would go away with time. When weeks turned to months and I was still not able to walk more than a few blocks, the pain began taking up more real estate in my mind. *What is going on? Why isn’t it getting better?*

I began to mistrust my body, which had once served me so well. I distanced myself. In my heart and mind, I stepped out of my body and away from the pain, vulnerability, and limits it represented. I told myself I shouldn’t be having such a disproportionate level of fear and anxiety over a minor injury. After all, it was just my body that was hurt. I—that is, my personhood, my locus of self, the consciousness that experiences the world—was still okay. Right?

Over and over, I found this wasn’t the case. Pain covered my whole self and my experiences like a veil. Life, even the most profound, celebratory moments (or perhaps especially those), took on a purplish, grayish tint. About a year into the pain, for example, on a lovely summer evening, my husband and I attended our friends’ wedding reception in their apartment complex courtyard. I put on an airy dress and tennis shoes, determined to enjoy myself and ignore the spasms and pinpricks in my back and ankle. Neighborhood refugee children from Sudan and Burma shrieked and threaded through the

tables while we devoured homemade tacos and salsa. When the music started, people of so many skin hues and accents streamed onto the patch of grass under strings of lights hung across the balconies. It was a beautiful picture of togetherness and harmony.

I had to join in. Dragging my husband, Matt, into the edge of the moving mass, I let the rhythm carry me. As I moved, though, the static noise of pain in my body rose over the other sensations—the freewheeling elation of dancing, children’s yells, Shakira’s voice through the speakers. For a brief moment, I had emerged from the cave of pain to join the world of the living. And then, so quickly, my body pulled me back into that cave. The angry, twitching knots in my muscles and joints took over my senses like a waterfall pounding down, drowning out sight and sound, veiling the outside world. The world of a person in pain, essayist Elaine Scarry writes, shrinks to the confines of her body.<sup>2</sup>

I retreated to my seat, trying to convince myself that I could enjoy this party just as well without dancing, but something in my bones told otherwise. I was made to dance, made to express joy through movement. If I couldn’t find a way to be fully present in my body, then something was missing. Some part of my life was inaccessible. This sense of “missing-ness” caused more pain than the physical pain itself.

### PAIN AND ITS COHORTS

The connection between my body and my being, which I had taken for granted growing up, was fraying. The pain forced me to step back and see my body in a strange new light. What mysterious, malignant forces were working within it to cause me such suffering? How could I have walked about so blithely

when at any moment cancer could strike, some environmental toxin could wreak havoc in my cells, or I could fall and break a bone and never recover due to some weird disease I might have? I could no longer trust my body. It was no longer good. I couldn't accept that my body was part of me, if it was this sack of disorder. It was Other. Or, if I really was my body and we were inseparable, did that mean I was broken and decaying at my core?

As I wailed over my uncooperative body, the depression, fear and anxiety began swallowing me whole. Every odd symptom fed hypochondria and dismay. The life I had once envisioned no longer fit my current reality. Instead of plotting the realization of my pet projects, my thoughts drifted toward tragedy.

One Thursday, in the middle of my job at the county courthouse, an email slipped into my inbox from the church office. I read and reread it, not comprehending. "Yesterday around 9:10 p.m. Jonan Eilam Pelletier was birthed to parents Jeff and Kimberly. He had passed away some time on Monday." Was birthed. Had passed away. How could someone be birthed when he had already passed away? It took me a while to realize Jonan Eilam had died in the womb.

I closed out the email and continued pecking at my keyboard, entering the names and addresses of the day's delinquents for my boss to send to lawyers, who would then mail these petty criminals to offer their services. But Jonan Eilam stayed with me long after I shut the laptop, drove home, and collapsed on the futon, my routine in those days. I felt a strange communion with him, as if he were a fellow soldier who had fallen. It seemed morbid, but I was drawn to something about Jonan Eilam's short life and much-too-early death. I wanted to turn away, because I felt like an intruder peering in on a

neighbor family's private grief. But I couldn't stop thinking about him.

Maybe this was why: knowing that others also deal with sudden loss made my own losses more bearable. I wasn't the only one. Life *was* crazy, just like it seemed. Other people were also asking *why*. Why do some bodies work and others fall apart? Why did Jonan Eilam die before birth while others live past one hundred? Why did my ankle start hurting out of nowhere while others put their joints through marathons and mountain climbs, coming out the other end just fine?

Perhaps, I thought, I was a bit like Jonan Eilam. My body and heart were also fragile and weak, maybe not strong enough for the crushing weight of living. Sometimes I longed to slip with him into a place where it was easier to breathe, where gravity didn't pull us down. That night, I penned in my journal, "Life is too much sometimes, for Jonan Eilam and me."

These kinds of thoughts pulled me apart from others in terrifying ways. The people closest to me looked on with concern but couldn't get down to those darkest places, where rational thought and hope slipped away. They couldn't jump out of their skin and into mine. And, as I discovered with my husband, they were humans with their own needs, limited in their ability to be there for me at those most inconvenient times when panic attacked.

It usually happened deep into the night, after I'd flopped around for hours like a dying fish trying to get comfortable, when I had nothing to distract me from the low whine of throbbing joints and fearful thoughts. One of those nights, not long after the apartment complex wedding, the thoughts came swarming, biting, pegging themselves onto my chest in droves so I could hardly breathe. *What if it's like this for the rest of my*



*life? Or what if the pain just gets worse and worse and I end up confined to bed? How can it have only been two years since that beautiful, rainbow-tinted day when we got married? We've spent half of our marriage with me in pain, complaining. What a drag for Matt. Now that I have nothing to look forward to in life, what am I even living for? How can I bear the rest of my life if it's like this?*

I tried repeating the Jesus Prayer. "Lord Jesus Christ, Son of God, have mercy on me, a sinner." Over and over and over. Still, the internal noise of anxiety rose, and I thought my chest might explode. I needed to do something, anything.

I turned to shake Matt. He groaned in an irritated sleep-drawl, "Whaaaat?"

"I can't sleep," I whispered timidly.

This was the umpteenth time I had woken him in the middle of the night to replay my fears and cry into his chest. I waited for him to turn and ask me what was wrong this time. To reassure me that I was going to be okay. Instead, he muttered, "I need to sleep, Luan! Can't it wait till morning?" and rolled over with his back to me.

If I had been hanging on by a thread, that thread snapped. Though my rational mind told me that it *could* wait, that nothing would change by telling Matt the same things I'd already told him a hundred times before, my heart was like a wild animal, trapped and getting more frenzied by the second. I crawled out of bed into the shadowy living room and stared. Then, sprawling on the floor in my blue and white checkered nightgown, I grabbed the nearest object, a jacket, and slammed it into the floor. I did this again and again, listening to the zipper and cloth slap against the wood and bounce off, working myself into a fever. I pounded my fists into the floor and gave voice to my demons. The sounds were guttural, choked, and

shocking. I was trapped in the cage of my own body. I couldn't even go outside to run it out. I was alone, and I couldn't leave.

At some point, Matt did get up. I guess I forced him to, with my foaming-at-the-mouth demonstration. He wrapped his arms around me. His tight grip and his chest—warm and solid—against my back gave me a reference point outside of my own unreliable skin and bones. I let the fury and fear tumbling inside me drain into another body. The buzzing swarm on my chest lifted, for a moment. I somehow managed to go back to bed and face another day.

### DARK NIGHT OF THE SOUL

I struggled to patch my faith onto the growing hole of despair in my core. There were no easy answers. I wanted to be healed. I wanted to be whole. Wholeness is a unity of parts, a fitting together of pieces into a seamless, coherent entity. I was anything but whole. I was falling apart on so many levels.

Though I could draw from a rich legacy of theodicy, people defending the goodness of God against the reality of evil, words fall short in the face of human suffering. I started asking questions that not many people I knew cared to answer. Questions like, *if the healing work of Jesus applies to the whole of us, including our bodies, what does that mean when you're always hurting? Can my fragile, suffering body offer anything to my understanding of a meaningful life, or must I ignore it in order to go on?*

Traditional Christian views that tell us we are more than our bodies only helped so much. Paul says in 2 Corinthians 4:16, “Even though our outer nature is wasting away, our inner nature is being renewed day by day.” I have always understood this verse to be Paul's way of dealing with the reality of our fragile, broken bodies. He is saying, “Okay, your bones may be

losing density, your hair falling out, and your blood vessels clogging, but your soul is alive and well.” Some strands of Christianity take this even further, teaching that our body doesn’t matter; all that matters is our eternal soul. Wholeness is only important in that we are spiritually whole, in right relationship with God and others. Body and soul live in separate realms and don’t mix. We go to the doctor to deal with our bodies, and to church to deal with our souls.

I internalized versions of these messages, some that others told me and some that I told myself: “Luan, you have to be able to tell God, ‘I will love and serve you with one good foot or two.’” “You can still be part of God’s kingdom, regardless of what’s going on in your body.” “Look at all that you still have—your family, a loving husband, friends, a job, graduate school. Don’t focus so much on your body. Just trust God. It will get better.” These messages were encouraging to some extent, lifting my gaze off my health woes and onto a larger reality. In other ways, they deepened the disconnect I felt with my own body and my disillusionment with the church.

I couldn’t find many people concerned with the nagging questions I had about how to reconnect my poor aching body with my poor aching soul. Rather, my suffering was often spiritualized by others. Once, I went up to a prayer minister at a church I was visiting. After listening attentively to my story, the woman asked, “Are you harboring any unforgiveness in your heart?” People in church tried to answer the unanswerable whys, claiming my pain was punishment, a test of character, or intended by God to accomplish some other end. But none of their answers addressed the question I was asking: How do I live in my body now? The gulf continued to widen between me and the body of Christ. Another instance of falling apart.

Finally, there was my relationship with God. As my depression and pain worsened and prayers for healing remained unanswered, my once vibrant prayer life, where I heard and saw tangible evidence of God's care for me, seemed to diminish to me moaning at the wall in my room. God appeared to have gone on vacation to Fiji.

I felt plunged into what St. John of the Cross described as the "dark night of the soul." It can be a rich place of deepening faith and spiritual maturity. The pilgrim gropes toward God not based on sight, but on faith. Going through it, though, is terrifying. That unshakable conviction I had in the past that all would be well in the end faltered. I questioned all I knew about God and how he worked. If God was good, and what was going on in my life was somehow part of his good purposes, then I wasn't so sure I wanted the "good" he had to offer. I was afraid to draw near to God, who was no longer the comforting, ever-present God I had known. I was afraid that maybe, if I pushed deeper, God would turn out to be shadows in the fog, a figment of my own wishful thinking. So I kept my distance from God. I stayed apart.

### BECOMING WHOLE

It has been ten years now since the pain first started. Since then I have finished a master's degree, started freelance writing, and become a mother to three little boys. I still have pain, but it's not nearly as much of a presence as it used to be. It comes and goes, though it never fully leaves. Certain positions, like sleeping frequently on my left side, and certain activities, like walking in flat shoes without support, bring it all back. When I get too physically ambitious, the pain is like an old friend who calls to say, "I know where you come from—dust and ashes. Ha! You can't fool me!"

I've learned to accept what my body is. Sometimes, even, like when I pushed a ten-and-a-half-pound firstborn out, I marvel at it.

I have wondered in these years if the ways we understand healing might not have contributed to my falling apart. What is healing, when one has a chronic illness? Can a person still be whole (not just spiritually whole, but *wholly* whole) when her body is not functioning properly and she is suffering? I believe so, though it takes some unlearning of what we have assumed the good, successful life to be.

I'd like to sketch a different vision of healing, one seared by unrelenting brokenness, pain, and disease. To heal, as I understand it, is to become whole.

The educator Parker Palmer writes, "Wholeness doesn't mean perfection: It means embracing brokenness as an integral part of life." When Palmer speaks of wholeness, he doesn't mean a perfectly functioning body, or even a worldview where all the pieces fit together. What he has in mind is closer to the idea of *integrity*. He uses Douglas Wood's meditation on a jack pine to illustrate:

Jack pines . . . are not lumber trees [and they] won't win many beauty contests either. But to me this valiant old tree, solitary on its own rocky point, is as beautiful as a living thing can be. . . . In the calligraphy of its shape against the sky is written strength of character and perseverance, survival of wind, drought, cold, heat, disease. . . . In its silence it speaks of . . . wholeness . . . an integrity that comes from being what you are.<sup>3</sup>

*Being who you are.* For many, chronic illness pulls the rug out from under our old identities, interests, and life pursuits. We

no longer know who we are, or who God is. We must find a new way to be.

It is tempting to wish to go back to a previous state, that “normal” life we had when good health was assumed, our bodies were reliable, and God could be found. Too many of us cling to this flimsy ideal when we desperately seek treatment and healing. But as my disillusionment with God and the church deepened and I realized that pain was unavoidable, I knew I couldn’t go back to the old normal. I knew too much darkness, too much loss, that I couldn’t unknow. Theologian Marva Dawn calls this a loss of innocence, a loss of certainty.<sup>4</sup>

It’s hard to imagine any other way to be whole than feeling sure of a good life ahead, with health, career success, family, financial stability—all those things people say are your birth-right (if you are a middle-class white American, that is). As I have let go of these things as givens and stared at the broken pieces straight on, however, I have sensed that there *has* to be another way to be whole.

### BECOMING FULLY HUMAN

If wholeness, as Parker Palmer hints at, is this ability to *be who you are*, then I want to be who I am now fully. I want to integrate these experiences of suffering and brokenness into my being—how I see the world and God and myself in it. I want to take my pain, this truth that I now know in my tendons and ligaments, and hold it up against the gospel of Jesus Christ—his incarnation, death, resurrection, and promise of second coming. Will there be resonance, connection, unity . . . wholeness? Will the gospel illuminate my experiences? Will my experiences illuminate the gospel?

In fact, the Christian story has a lot to say to our pain. While some may think of faith as victory over pain and suffering (which it is ultimately), what we see in Jesus' life is not an escape from the everyday drag of having a body, but an embrace. Including all the discomforts, inconveniences, and embarrassments that come with it. *God became a human body*. What's more—*God still is a human body now in the resurrected Christ*.

I will explore this truth from the perspective of chronic illness. Healing is not an escape from the limits, vulnerabilities, and suffering of the body, but rather, it is becoming whole—becoming *who we are*. We are souls in bodies, but we are also bodies with souls. We will never *not* be bodies, even though implicit messages we have heard in the church may have misled us to believe we will one day shrug off all physical encumbrances. The new creation, theologian N. T. Wright declares, will be “a new kind of physicality, which will not need to decay and die . . . *more* physical, more solid, more utterly real.”<sup>5</sup>

To heal, to become whole, we must embrace the truth of who we are—a triune personhood of body, mind, and soul—in light of who our triune God is. We must learn to be fully human, not *superhuman*, by living within our embodied limits, not transcending them. We must make peace with our tenuous existence, susceptible at any moment to devastating illnesses and even death. We must realize that our vulnerability is what opens us to relying on others, and, through these relationships, becoming whole.

Chronic illness, though a tragedy, forces us to pay attention to our bodies. Due to our longer life spans as well as other factors, a growing number of people have chronic illnesses—conditions that go on indeterminately and don't respond quickly to treatment.<sup>6</sup> Some of these illnesses, like heart disease

and diabetes, are widely recognized and can be managed by standard treatments (though they are still difficult to bear). Others are “invisible illnesses” that don’t manifest in measurable, obvious ways (fibromyalgia, chronic fatigue, and lupus are examples). These bring added suffering due to the lack of recognition and social support. This book is for all who struggle to make sense of how the God of the gospel meets us in our broken bodies, especially those who have felt unheard and unsupported.

### A WAY FORWARD

In the coming chapters, I will deconstruct and reconstruct our understanding of wholeness. I will also share my own story and bring in the voices of others who have graciously entrusted their stories to me. Over coffee, phone, video chat, and email, these people have let me interview them, allowing me into those hurting, wondering places where God and illness do not make sense. Their stories, which are interspersed with my own, do not have a neat bow tied at the end. They are stories of people wrestling, questioning, staggering, sometimes making peace, sometimes not. These are the stories I wish I had heard in the valleys of pain. They ring true and speak to our resilience. If we can press into them, and not shy away from the shadowy spots where meaning evaporates and only groans remain, maybe we will find, in the darkest pits, the God who descended even deeper, who shows us a way through to new life.

Though I use chronic illness as a lens, my questions are not unique to that experience. The aging and disabled also know bodily limits and vulnerability well. Admittedly, what I describe here is the experience of being thrust into pain or illness in the



middle of life, often abruptly. This is different (though not necessarily harder or easier) than being born with a disability or illness and learning early on how to accept these givens and integrate body and identity. For example, many in the deaf community don't see their deafness as *lack of hearing*, but as a culture with its own language and meanings. Those in the disability community have paved the way for the rest of us to reimagine our identities and bodies against the grain of "normal" functioning.<sup>7</sup>

Aging, on the other hand, is an expected life stage, though this doesn't make the loss of physical capacities any more bearable. Mental illness, too, brings to the surface the depths of our human condition—our darkness, our unchecked impulses, our lack of control over our external and even internal states of being.<sup>8</sup> Many of these categories overlap, and often one leads to another. Illness, for instance, might lead to a permanent disability, or chronic pain might lead to depression and anxiety (as it did in my case), which are forms of mental illness. And all of us, at one point or another, will have some of these experiences. Though we often see our health and able-bodied capacities as the default, it would be more accurate to see them as the extreme end of a spectrum, with most of us falling somewhere in the middle and moving back and forth throughout our lives.

Because my questions are not unique to chronic illness, I hope my reflections will benefit not only those with chronic illness, but all of us who follow our enfleshed Lord. We are all members of him, and of one another. We have, sadly, often dismissed experiences of chronic illness because we prefer tidy stories of immediate healing. We'd rather cling to our ten-step formulas and the misguided hope that if we follow the

rules and do the right things, we will avoid major suffering. If we take chronic illness seriously, we must question these assumptions. We must face pain and suffering as unavoidable realities of life and find ways to integrate these experiences into our life vision. We must open ourselves to lament, paradox, and mystery. In doing so, we will find ourselves joined to each other in a unity deeper than our aching bones, joined to God who binds all our wounds and makes something more, something beautiful, out of it all.

May we journey closer to this kind of wholeness. May those with chronic illness and pain embrace their hurting yet still-so-wonderful bodies. May the church embrace her broken yet still-so-necessary members. May we heal from ways of thinking that dishonor our bodies and deepen the rifts between our bodies, minds, and spirits.

Lord Jesus Christ, have mercy upon us. Lord Jesus Christ, make us whole.

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