DEANNA A. THOMPSON

GLIMPSING RESURRECTION

Cancer, Trauma, and Ministry



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FOREWORD

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Undone and **Redone**

The makeup of our psyche or our systems of support really do not matter; we can be undone. Pain and suffering deconstructs us. It pulls us apart. This is the reality of being creatures created out of nothing. We have no inherent stability, no bodily mechanism that guarantees eternality. The truth of the creation and of every living creature is our contingency. We did not have to be; but because we are, we are loved by God, our creator. The real question that flows out of such knowledge is "How can we live with such knowledge?" This is a different question than questions of theodicy.

Theodicy questions revolve around the idea that God—as the all-powerful and controlling progenitor of all that exists—is in some fundamental way responsible for pain and suffering. This concept begets another tragic idea: that God observes our pain and suffering and could do something about it, if God wished to do so; but for reasons beyond our understanding, God does not act on our behalf. Theodicy questions circle these ideas, drawing energy from them. Such questions always drive people into endless, exhausting searches for answers that they will never find, because theodicy questions are always self-enclosed. Theodicy questions are bad questions. I write this not in any way intending to be insensitive or theologically elitist but fully recognizing the folly of questions that flow out of ideas of an abstract, all-powerful, and controlling God bound to realities of inexplicable and explicable human suffering and pain.

The problem is not that we ask questions of God in the face of pain and suffering. The problem is that we are often trapped in asking the wrong kinds of questions, questions that are in league with our becoming undone and allied with our deconstruction. The task of Christian theology and the calling of Christian community is to help people ask the right kinds of questions. This is our birthright and our great joy found deeply inside the character of Christian witness. We theologians, for our part, dance constantly with the questioning-stepping now this way and now another, avoiding death-dealing questions, moving quickly toward life-producing questions - always seeking to discern the difference in questions, always watching for questions that start off badly but then move toward the good or questions that begin with the best of intentions but quickly become toxic. This is not heroic work because theologians are surely not heroes. We are only those who are called to give witness with all the people of God to a God who has joined the divine life to the life of the creature. We testify that the God who creates has been joined to the creature that questions.

A creating God and a questioning creature are meant for each other. This is the logic of love born of the creation itself. God planned for communion and aimed for a reciprocal speaking and hearing: "Come now, let us argue it out, says the LORD" (Isa. 1:18a). The divine desire for communion is not the reason for our pain and suffering. It is God's response to that pain and suffering. In becoming human, in bearing and being the story of Israel in Jesus of Nazareth, God has turned our questions toward communion. This is the heart of the matter. The difference between good and bad questions pivot around communion. Those questions that drive us away from sensing the heart of God for us are bad questions, not by their quality, character, or texture, or even their intensity, but by their direction. They are not aimed at the real God but at a fiction, a fantasy of God—all-powerful and inscrutable, who weaves together mystery with maliciousness. Good questions are intense and personal, urgent and angry, and relentless, always wanting to hear and know, see and sense God responding. Such questions begin with the real God: a God who is touched with the infirmities of the creature and the creation, acquainted with grief, familiar with sorrow and with very bad news. This real God found in Jesus knows rejection, isolation, relentless pain, and what it feels like to be undone. Starting from this sure knowledge of this real God, the triune God given to us in Jesus Christ, the real questions can begin, and a struggle that is itself already redemptive comes into view.

To make a struggle redemptive is not to glorify it, and certainly not to imagine it as a providential plan of God, but to allow it to be a struggle with God, bound up in God's own life with us. I constantly tell my students, those aiming to be a pastoral presence to suffering people, that coming alongside people as they ask questions of God and as they struggle with suffering and pain is one of the greatest privileges of Christian ministry. It is an art of ministry to know how to help people form and articulate their own questions in ways that draw them toward communion with God. It is an art that demands a lifetime of cultivation through patiently listening to people and yielding to the Holy Spirit who guides us into truth. This brings me to the work of theological writing, writing at the sites of hurting people who are sincerely and honestly asking questions.

Writing theology is always difficult work, because it is such an audacious act. Who would dare write about God and write in the aftermath of the word of God—spoken, written, preached, and embodied? Who would dare imagine that they could write about all creatures and the creaturely condition as a singular creature? And who would dare write about the intercourse of divine word and beloved creatures with confidence, assured that they had a duty and a calling to do so. Only theologians write like this. When we do, we find we must live with the consequences, such as (a) being ignored and sometimes ridiculed by other intellectuals who think such writing is ridiculous; and (b) standing under the judgment of a God who considers every word we say, especially to and about those who suffer. Yet there is another dynamic that marks the writing of a theologian: we write as fragile bodies even as we write about fragile bodies. Some theologians forget this dynamic, and their writing shows that forgetfulness. These are those whose lust for cleverness and a sterile articulation overwhelms the creaturely nature of theological witness. They become a talking head. There are, however, other theologians who never forget that they are fully body. Admittedly, it takes a special theologian, a stunning Christian intellectual, to write at the site of pain and suffering while being themselves a site of pain and suffering.

This kind of writing cannot be adequately captured with the label of "autobiography," because something richer and far denser than memoir happens with such writing. It has the character of the one speaking with the many, and the feeling of a multitude and a single life merged together without the one ever canceling out the other. The best theological writing about suffering has this character, but unfortunately such writing is rare. Fortunately for us, Deanna Thompson writes in this way and has been doing so for a long time. Theologian Thompson brings a beautiful precision to an engagement with pain and suffering through her focus on cancer. She has needed such focus in order to struggle with cancer's undoing of her life.

Deanna Thompson gives us words to fight against cancer. Her words fight against the way the diagnosis of and struggle against cancer can destroy our souls and strangle us in despair. Thompson, the extraordinary theologian and cancer survivor, allows her words to give powerful witness to God's words and, in so doing, has written a book for the ages. As long as people fight against cancer and as long as theologians, pastors, and congregants have to think through cancer with their faith, Deanna Thompson's book will be a celebrated ally and a welcome friend. But Thompson's words will also help people find their way to the right questions to ask God and the best ways to position their struggles as a shared project with God, even and especially if they imagine they struggle against God. There is no sin in imagining that we struggle against God in our suffering. God will not be our enemy in such imaginings but will through the Holy Spirit seek to reveal the divine life joined to our suffering. The Apostles' Creed teaches us to confess that "Jesus descended." We serve a God made known to us in Jesus Christ who has claimed the spot at the bottom: at the deepest places of anger and shame, of exhaustion and frustration, of despair and abandonment, where there is no possibility of digging a deeper hole or of grasping even more nothingness. Jesus descended to that place, and he will meet us there with the power of a God who will not let the descending be the last action. Being there with Jesus is the beginnings of our resurrection. This will be the first action of a new life—life eternal. The body will be redone. And even in the depths of despair with him, we can glimpse what is to come.

Willie James Jennings

INTRODUCTION

In December of 2008, I was diagnosed with stage-IV breast cancer. Life became virtually unrecognizable; I went from being a healthy, active forty-two-year-old wife, mother, daughter, sister, professor, neighbor, and friend to being a virtual invalid with a life and family in crisis and a lousy prognosis for the future. By the time I was diagnosed with metastatic breast cancer, the cancer had spread from breast to bones, fracturing two vertebrae and camping out in my pelvis and hips. The intense treatment regimen radiologists put me on made me even sicker, leading to trips to the ER and a New Year's Eve in the hospital where my husband and I ushered in a new year by making plans for where I would be buried.

While family and friends immediately sought out statistics on my prognosis, it took being weaned off oxycodone before it occurred to me to hunt down those numerical predictors of my future: the statistics that said that five years out, 80 percent of people who have what I have are dead. I'm a religion professor, an expert talker who gets paid to talk about God. But being diagnosed with a *breast* cancer that crushes vertebrae and comes with sobering prospects about living long or well with the disease conspired against me. I had trouble locating words for this kind of cancer, trouble with words for (or $\partial irecte\partial at$) God, trouble with words about the possibility of living with or in spite of it.

Effects of treatment and back surgery made death's nearness seem stiflingly close. I had trouble getting out of bed and dressing myself; I couldn't drive to and from the mountains of appointments. I resigned from virtually every part of my full and wonderful life, and I struggled to get back in the classroom to teach one final course. I hoped it would bring some closure to me and the campus community I loved so much. That classroom seemed to be the only space where cancer did not dictate all the terms of my life. Outside those three hours a week where I played the role of teacher, I was a cancer patient who seemed to have little time left.

When I cried my way through an entire oncology appointment, my oncologist suggested that I visit a cancer counselor to help me cope with my new life. The cancer counselor encouraged me to write letters to my preteen daughters that they could open on their graduations and wedding days where I expressed how much I wished I could be there to celebrate their special days.

But as winter turned to spring, the pain from back surgery receded enough for me to remove the Fentanyl patch on my arm and begin physical therapy. My twelve-year-old received an award at school for persevering in the face of adversity. I started driving again and found the energy to make a couple of meals a week. The back brace that had held my spine together moved to the attic, and at the beginning of summer, we resumed our tradition of family bike rides to a local lake. After months of being overwhelmed by the incurable status of my cancerous life and fearing the end was near, I went into remission—a lovely, disorienting state of being.

Friends and family threw me the party of a lifetime, and I interpreted my cancer story in light of the dominant version of the Christian story I had come to know so well:

And in this feasting amid the crying and the grieving, my life mapped the movement of the Christian gospel story in a way I never imaged it could: I have experienced firsthand a death and a resurrection. I have witnessed new life growing out of the ashes of death and destruction. It doesn't get more Christian than that.¹

For months following my diagnosis, it looked like my stage-IV cancer story would swallow me whole. When it didn't, it was the Christian story that helped make sense of what had happened. Dawn had come. I had been given new life.

Yet in the past nine years, I have lost and found remission again and again. And while any day with remission is better than any day without it, there are many days when the death-tonew-life story line seems too constricted to hold the frayed edges of life with cancer. From the earliest days of my cancer story, the diagnosis-treatment-survivorship plotline also has seemed too streamlined, too linear to allow enough space for the incurable version I'm living. The fickle status of remission and the ongoing oncology visits and chemo treatments leave me searching for more spacious versions of the stories that interpret my life.

Before cancer, my work as a theologian and academic focused largely on questions of justice; I'm a Lutheran, feminist scholar who teaches religion through the lenses of gender and race. My family and I are part of a community of faith that understands the call of the gospel as a call to stand with those whose lives bear the marks of injustice. But getting sick has opened me to a world of hurt that can be hard to see and hear when our notions of the Christian story, Christian community, and Christian mission are cast primarily within a moral framework of justice. Don't get me wrong: I'm not interested in *less* focus on justice. But I am interested in cultivating greater consciousness of the suffering that *simply is* so that we can make more space for it, not just within our tellings of the Christian story but also in our embodiments of Christian community and our sense of what it means to share the burdens of those who suffer.

Illness, Anomie, and the Christian Story

Each of our lives bears the marks of suffering, and when we face intense experiences of suffering, we crave explanations for the "*Why*?"—answers for why things happen the way they do. Knowing why reassures us that we live in a *nomos*, an orderly world that operates according to understandable laws. We want life to make sense. We want things to happen for a reason. Society and religion provide us with what scholars call nomic structures within which we make sense of our world and the subplots of our lives.²

It is not surprising, then, that dominant versions of the cancer story strive toward nomos by placing life with serious illness in a moral framework. Those of us who live with cancer are cast in the role of warriors called on to battle the cancer with all the ammunition we've got. Telling cancer stories through the use of military images provides a logical framework for illnesses like cancer: cancer gets cast as an evil invader, and those of us who have the disease are called to take the moral high ground by fighting and ultimately defeating it.

It's also not surprising that a moral framework tends to remain in place when the cancer story meets up with the Christian story. The question of why becomes an insistent one. Why would a good God who overcomes moral evil allow illnesses like cancer to exist? Where's the justice in diagnoses of cancer? We crave nomic answers from a religion built around just conceptions of God, but when we pay attention to the lives of those with life-threatening illness - whether they are religious or not - the most insistent question tends less to be "Why?"-for so many of us, there's simply no logical explanation for why we were stricken with serious illness-than "How?"-as in "How do I live into this reality that is now my life?" For those of us who claim the Christian story as our story, the most pressing question becomes "How does the Christian story offer a framework of meaning to this cancer-filled life where meaning is constantly under threat?"

When events like a cancer diagnosis occur in the absence of any clear explanations, we are confronted with *anomos*, an unordered, unstructured, even lawless sense of the world. Unexplainable evil, or that which seems to be unexplainable, threatens the nomos by which we make sense of our lives. What's needed in our theologies is more space in the tellings of the Christian story—as well as in communal enactments of that story and the living out of the story's call to care for those who suffer—for the anomie that comes from living with serious illness.³

Pauline Boss, whose research on those who live with ambiguous loss—loss that lacks finality and resolution—suggests that the challenge in these situations is to bring clarity to an ambiguous situation. Failing that, and Boss notes that in most cases our attempts at clarity *will fail*, "the critical question is how to live with ambiguous loss."⁴ The hope is that we can learn to live amid the loss, balancing our grief over the chaos that serious illness ushers into our lives with a recognition of what kind of living is still possible. It is my claim that using the lens of trauma to help understand losses brought to us by cancer will aid us in balancing the grief with a vision of how to go on, even amid enduring loss.

Trauma and Cancer

Trauma is "the suffering that remains"⁵ in the aftermath of events in people's lives that threaten to overwhelm their ability to function. The growing field of trauma studies⁶ is helping develop a deeper appreciation of how experiences of trauma foster that sense of anomie. Research documents how the invisible psychic wounds of trauma disorient and upend the lives of those who have endured awful events.

In the 1990s, life-threatening illness was added to the list of events and conditions that can cause post-traumatic stress disorder (PTSD).⁷ In so doing, psychiatrists were acknowledging that the threat to life and bodily integrity due to cancer or other serious illnesses can precipitate deep senses of fear, devastation, and lack of control—all symptoms of post-traumatic stress. But applying a post-traumatic stress diagnosis to those who live

with life-threatening illness remains an unsettled issue, as there are ways in which trauma associated with illness does not fit neatly into the diagnostic framework of post-traumatic stress. While conventional understandings of traumatic events focus on extraordinary occurrences in the past that have a beginning, middle, and end,⁸ trauma associated with illness typically does not arise from a single event but rather from recurring events extending from diagnosis through treatment and beyond, possibly throughout the rest of a person's life.⁹ Given this reality for people living with serious illness, researchers wonder whether those living with cancer can ever become "post-trauma."10 The distinctive manifestations of cancer-related trauma reveal that the precise nature of the trauma can remain unclear, and subsequently, the post-traumatic stress condition of reexperiencing the trauma fails to adequately capture the ways in which "the suffering remains" for those living with cancer.¹¹

While the majority of people living with cancer do not meet the criteria for a cancer-related post-traumatic stress disorder diagnosis,¹² many live with one or more of its symptoms. One study of cancer patients shows that about a quarter of patients experience intrusive or distressing thoughts or dreams related to cancer. A sizable minority of people living with cancer also experience emotional numbress or avoidance of thoughts and feelings associated with diagnosis and recurrence; another quarter report hypervigilance and physiological arousal as common; all of these are symptoms of post-traumatic stress.¹³ Few studies, however, have yet to limit their focus to a single type of cancer at a specific stage; therefore it remains difficult to compare findings when the types and stages of cancer-as well as treatment protocols and whether patients also have current or past psychiatric illnesses - have yet to be adequately taken into account. To make diagnosis and assessment even more complicated, there is not yet a widely accepted instrument to screen for post-traumatic stress in patients with cancer.¹⁴

Nevertheless, the studies that have been conducted ∂o attest to what researchers call the *chronicity* of cancer-related experiences of trauma—the ongoingness of treatment for the disease along with the risk of recurrence for those whose cancer is not deemed chronic. The chronicity of the condition influences the ongoing character of the post-traumatic stress symptoms experienced by those living with cancer. One study demonstrated that a year after treatment ended for forty-six women with breast cancer, no significant improvement could be documented in symptoms of post-traumatic stress reported by the women in their initial and follow-up interviews. In fact, more than one in ten participants reported an *increase* in symptoms of post-traumatic stress. Even twenty years out from chemotherapy, one in seven women treated for breast cancer continued to experience two or more symptoms of post-traumatic stress that were moderately or extremely bothersome.¹⁵

Even though trauma's relationship to cancer receives sustained attention within the realm of medical research, only a fraction of people living with cancer who report levels of psychic distress currently receive any type of psychosocial therapy.¹⁶ With estimates of fifteen million new cases of cancer diagnosis to occur in the year 2020,¹⁷ arriving at a better understanding of how the psychic wounds of trauma affect those living with cancer is vital to helping them (us) live with potentially damaging psychosocial effects of the disease, and hence live better, even well.

While important similarities exist between the ways that trauma works in the lives of those who've endured acts of violence and the lives of those who live with life-threatening illness, one key difference between the two is this: rather than being an enemy invasion or threat from the outside, illnesses like cancer are primarily *internal* threats. Augustus Waters, the teen-aged protagonist dying of cancer in John Green's novel *The Fault in Our Stars* wonders out loud, "What am I at war with? My cancer. And what is my cancer? My cancer is me. The tumors are made of me. They're made of me as surely as my brain and my heart are made of me.^{"18} That our cancer is "us" creates a distinctive way of experiencing the trauma related to living with this internal reality that threatens to kill us.

"It is the emotional part [of living with cancer] that becomes the greater challenge," admits Rodney, a husband who takes care of his spouse living with advanced-stage cancer.¹⁹ Regardless of whether those who are seriously ill have diagnosable posttraumatic stress, applying the lens of trauma to those living with life-threatening illness deepens our understanding of the range of emotional responses that occur when living with cancer; it opens up more breathing room for those who live with cancer; and the lens of trauma offers those who care for people who are really sick a broader framework in which to offer that care. Sociologist of illness Arthur Frank argues that when those of us who are ill get to tell our stories and have them really listened to, the potential for healing increases.²⁰ This is especially important work for Christian theologians, clergy, and communities of faith: envisioning what it means to be the body of Christ to and with those who suffer.

As a theologian living with incurable cancer, I've become more aware of how our versions of the Christian story bend toward resolution while the plots of our own lives stubbornly resist it. One of the key insights from trauma studies is that living in the aftermath of traumatic events requires negotiating the ways in which traumatic aftereffects interrupt life in the present. When insights from research on illness-related trauma are placed in conversation with theologians who take other types of trauma research seriously, it becomes possible to contribute to a more expansive telling of the Christian story, one that makes more space — theologically, pastorally, and ecclesially — for the traumatized, particularly those traumatized by serious illness.

What's Ahead

If we move beyond the confines of battle imagery and tidy frameworks of the meaning of illness, what is it that we hear from those who suffer from serious illnesses like cancer? Chapter 1 begins there, listening to cancer stories that expose dimensions of living with illness that make it so difficult to be ill—and to be with those who are ill—places where the anomie related to cancer becomes most insistent and acute. These stories offer glimpses not only into the most unsettling aspects of being sick but also into some ways in which those whose lives are undone by cancer manage to find ways to continue on.

Chapter 2 utilizes recent work in trauma studies to explore in more depth the most unsettling aspects of the cancer stories discussed in chapter 1. These examinations help sharpen our understanding of the distinctive ways in which the ongoingness of illness-related trauma—a trauma that often emerges largely outside networks of moral evil—operates for those who live with it.

Chapter 3 builds on insights of theologians engaging trauma studies to explore those places in the Christian story that make space for expressions of anger, protest, and anguish that come from being seriously ill. Exploring space for illness-related trauma amid the psalms of lament, the story of Job, the godforsaken Christ on the cross, and Holy Saturday helps expand boundaries of conventional tellings of the Christian story. The chapter focuses on moments in the biblical narrative where movement beyond the bounds of moral framing is glimpsed, where space is created to be in relationship to God amid lifethreatening conditions—space that allows room for protest, anguish, trust, and praise.

Listening to some of the ways cancer undoes those who live with it, using the tools from trauma studies to see more fully the suffering that remains for those who are sick, and making more space in the telling of the Christian story for those undone by serious illness all lead to a vision in chapter 4 for what it means to be the church for those who are undone by suffering—particularly the suffering that has no easily identifiable perpetrator. From embodied rituals of lament and healing in worship to forms of care embodied and lived out in and through community, those undone by illness witness an acknowledgment of their suffering and are surrounded in ways that help assuage feelings of despair, even when the anomie remains.

All of this leads, finally, to hope. The concluding chapter explores the ongoing challenges of living with a chronic illness. Turning to Paul's exhortation in 1 Thessalonians 4 that Christians should grieve not as those who have no hope, I explore the relevance of Paul's vision for ways to affirm the irresolute, not-yet-resurrection time in which we live as also a time of hope for the healing that comes from being able to grieve while also hoping in the more of God's future.

Exploring what it means to be undone by serious illness using the language of trauma, identifying more spacious tellings of the Christian story, and finding images of Christian community that open up more room for the undone all provide, for me, an exercise in hope. It doesn't make sense of my own intimate acquaintance with cancer, but it helps me glimpse a divine future that opens more pathways for living with serious illness in this not-yet-resurrection time. My hope is that it will open up similar pathways for others who live with the death-dealing realities of serious illness.