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AN ALTERNATIVE ORTHODOXY

LIMINAL SPACE

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The Art of Spiritual Companionship

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> *When I am in that darkness, I do not remember anything about anything human.*
>
> —Angela of Foligno

There are likely few situations with the power to reliably propel us beyond the threshold of everyday existence and into the realm of the liminal than the way of the despair of receiving a diagnosis of a serious, life-threatening illness. It can feel like being hit by a brick or like being hurled into the dark abyss. Once there, the territory can be utterly disorienting and terribly frightening.

It is also difficult for us when a loved one enters that dark place. We go there with them, but only as far as we allow ourselves. We much prefer to avoid painful emotions like uncertainty, fear, grief, or despair and tend to evade them. Especially in our fix-it culture, family and friends preoccupy themselves with *doing something—anything*—to

help. For doctors, nurses, therapists, and other healthcare providers, the focus is on the interventions they can offer—curative or palliative.

These actions that families and health professionals perform can certainly be good and necessary, but they can also be distancing and isolating, keeping us from truly being with the sufferer. In turn, they bring about a sense of abandonment for the person whose life hangs in the balance. Few know how to enter the liminal space where their loved one or patient has been forced to go, let alone how to *be* there should they be brave enough to dare to enter. We are uncomfortable in these kinds of liminal spaces because it is strange and unfamiliar territory, woven with the difficult feelings we've been taught to suppress by medicating them away, bypassing them through platitudes—"Be strong!"—or denying them altogether. Consequently, it can be a lonely place for a person having to face the vulnerability of their fragile mortality. Tragically, I have seen and experienced many a friend and family member—myself included—who could not stay in the presence of their loved one's emotional or existential despair. For a physician, it may appear in the form of avoiding a terminal patient at the most critical stages of their illness.

As a chaplain, my role in caring for seriously ill patients is to enter these spaces and *suffer with* them. This is the literal meaning of the word compassion, from the Latin *pati*, suffer, and *cum*, with. I am not to fix, not to deflect or distract, and certainly not to avoid, but instead, as Henri Nouwen and colleagues have written, "to go where it hurts, to enter into places of pain, to share in brokenness, fear, confusion, and anguish."[1] This is the best definition of the practice of chaplaincy and the art of spiritual companionship I've found. It takes willingness, fortitude, knowledge, skill, and a deep trust in Spirit to go into these dark places as both witness and companion.

To be very clear, I am not equating darkness with something bad or negative, any more than I would consider the apophatic way as such. There is deep beauty in the darkness, in the unknowing, in the indescribable, if only we can open ourselves to its purpose. Metaphorically, the *dark emotions* of grief, fear, and despair can be profound teachers and guides, or, as psychotherapist Miriam Greenspan writes, the "raw material of spiritual empowerment and

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transformation."[2] The primal howl of existential suffering holds within it the lesson that we all must learn at some time in our lives: To heal from our suffering—not merely to ease or palliate it, but to transform it into the source and substance of our growth and wisdom—requires a journey through it. We must listen attentively for whatever message it has for us and, according to Greenspan, find authentic ways to befriend it so that we can surrender to its transmuting power. All spiritual traditions teach some variation of this wisdom. While it may not come naturally to us to respond to suffering in this way, through practice, it can become a learned skill. This is the art of spiritual companionship.

I would like to share a story of a journey through the dark liminality that I encountered while companioning cancer patients at a community hospital as their chaplain. Late one afternoon, I received a page from the unit clerk, "Mark,"[3] informing me that a patient's sister was requesting me to visit her brother, Larry, a sixty-year-old who had just been admitted. When I arrived, Mark rushed over to me, nervously adamant that I should not go in to see the patient until I first spoke with the sister (per her request). He further shared that she was a nurse in another hospital. At that point, the only thing I knew was that the patient (Larry) was newly admitted to the unit with a diagnosis of advanced pancreatic cancer. Mark asked me to wait until he could let Monica, the sister, know I was there.

He went into Larry's room alone and asked Monica to step out into the hallway. She was a very pleasant, middle-aged woman dressed in jeans and casual plaid shirt. Her demeanor was calm, which allowed me to relax and let go of any anxiety that Mark's energy had created for me. After introductions, she thanked me for coming and then said something like this: "I'm deeply worried about

Larry. I don't think he's being realistic at all about what is going on. He knows he's dying, but he refuses to accept it. I'm a nurse and I see this all the time."

Standing in the hallway felt awkward, so I invited Monica to join me in one of our family waiting rooms where we would have more privacy and comfort. As we walked down the corridor, I was overcome with sadness. Hearing Monica describe her brother as being unrealistic catapulted me back to conversations I'd had with my own brother, Ira, years earlier, as he was dying from cancer. I tried to convince him — even to the point of arguing with him — that it was time for hospice. Ira had tried every reasonable combination of chemotherapy and radiation, none of which had halted the progression of his disease. Even his oncologist had suggested it was time to consider hospice, but my brother refused, and continued to try to enroll in any clinical trial he could.

It was difficult to hear the painful and poignant details of how he had contacted every medical center in the Baltimore-Washington, DC area, desperate to get into any experimental study related to his cancer, only to receive the heartbreaking news over and over that he'd been turned down. Then, when that failed, he took the Acela train in the muggy heat of an east coast August to the Memorial Sloan Kettering Cancer Center in New York to try to enroll in a trial there, only to be told he wasn't eligible. Despite that, he still refused to consider hospice. I had felt anger at what seemed to me to be a futile and foolhardy effort on his part but, short of relentlessly encouraging hospice, kept those thoughts to myself. Recalling that and empathizing with Monica, I thought, *this must be so difficult for her*.

Once we were seated comfortably in the waiting room, I recapped what I'd heard her say. "You say you are worried and that your brother isn't being realistic…?"

She responded, and this time her voice was stern. "He's dying. The cancer is now so advanced that even his doctor says there's no more chemotherapy that can help, but he keeps wanting to try something else. There isn't anything else. We want him to be as comfortable as possible and asked for hospice, but he is refusing. That's why I want him to speak to a chaplain. Maybe he'll listen to you."

Despite her focusing on Larry, at that moment it was Monica, the sister, with whom I was concerned, so I probed further. "I am so sorry to hear about your brother. This must be very hard on you."

"What's hard is watching him suffer needlessly," she replied. "He's always been the stubborn one." After a bit of silence, she added, "It's hard on all of us. There were five of us originally. We were a good Catholic family," she laughed, "but two have already died. Most recently, two years ago, Bob died. Larry was by his side the whole time, so he knows what dying looks like. He really didn't take Bob's death well."

"Oh my! You've been through the loss of another brother recently. So, I imagine that makes Larry's condition even harder for you—to experience another loss of a close sibling. I am so sorry to hear that."

I watched the sternness in her face and voice fade as she looked downward and said to me, "We were all very close." At that point, it was hard to know whose suffering was more urgent for her—her brother's or her own. Then the energy returned in her voice. "But Larry is in denial and *it's all wrong*! Especially when he doesn't need to suffer. You know what hospice can offer. He just isn't being realistic!"

I was fully aware that once again she had deflected discussing her feelings, so I tried a different approach: "You also mentioned that you are a nurse and that you 'see this all the time.' Can you explain what you mean by that?"

Her back straightened as she leaned forward. "What I meant was that I've seen so many people who were in the same condition as Larry, who just wouldn't let go, and I watched them suffer through chemotherapy or radiation that just added to their suffering. Larry has an advance directive that states he wants a full-court press—he wants everything done, but that's ridiculous. When you see him, you'll see how frail he is."

The word *ridiculous*, applied to her brother's stance, resonated with my sense of my own brother's *foolhardiness*. "Monica, I know it's hard to professionally witness that kind of suffering in others. It's even harder when it's your own family." I wanted to acknowledge her suffering as well, but she wouldn't let me, staying her course like someone on a mission and restating her desire for hospice. "Especially when there are alternatives that he's refusing," she interrupted.

Here was an insider's view of liminal space—*being alone in the emptiness of the darkest blackness.*

After sitting together awhile in silence, she finally said, "I think Larry is afraid of dying and I'm hoping you can talk to him. Maybe if he could speak to you as a chaplain, maybe he'll break out of the denial and won't be so adamant about refusing hospice."

So, these were my marching orders. I wanted to make it clear to her what she was asking of me, both explicitly and implicitly.

"I can certainly talk with him about his fears if he wants to. But I also kind of get the sense you'd like for me to soften his stance about hospice."

"Yes, that would help." After a long pause, she added, "Why don't you go in to meet him now." I agreed and asked her to wait in the family room while I went in to speak with him alone, promising to come get her after we'd spoken.

I headed to Larry's room, knocked on the door, introduced myself, and then walked over to his bedside. Larry had large deep-set blue eyes, exaggerated by their sunkenness into the hollows of his wasting cheeks and face. He was significantly thin, yet when he smiled, his whole face lit up. I felt welcomed by that smile. "Hi," he said, "come in. Please sit down. You spoke with Monica?" I nodded, yes. "Then you know that my cancer is real bad. She wants me to go into hospice, but I don't want that yet. It's not time."

It took me just a few seconds to position a chair to face him so that I could speak at his level. "Yes," I replied, "she mentioned that. But I'd like to know what you are experiencing right now."

Larry's frail arms reached up and then, *kerplop*, dropped, landing on top of his head. "I feel like a brick just fell out of the sky and hit my head and I don't know what to do. They just told me that the cancer is now out of control. I had chemo and radiation, but I guess it didn't work. The doctor said there is a possibility of more chemo even though he didn't recommend it. But that's what I want."

A part of me left the room for a fleeting moment—intensely aware of a similar conversation with my own brother when he had refused hospice. I felt a bittersweet sadness over the missed opportunity to be my own brother's spiritual companion when he had needed it most, yet I also felt deep compassion for myself, for Monica, and now with Larry, which helped bring me back into the room.

"I'm trying to imagine how that might feel, getting such devastating news, with everyone trying to decide what's next for you—like getting hit by a brick, as you say."

What Larry said next was one of the most profound things I'd heard since entering the field of palliative care.

"Yeah, Monica says I should focus on my quality of life. *But there's no quality of life without life.*"

I was floored by this deep insight. It seemed to contradict one of the primary tenets of palliative care—*to improve the quality of life of patients and their families facing the problems associated with life-threatening illness*[4]—that had guided my professional work. "That is profound, Larry. Wow—'there's no quality of life without life.'" After a long pause, I said, "I am hearing that you want to live and that you are willing to try more chemo even if the chances are slim that it will work."

"It's all I've got. I don't want to die."

"It sounds like you have given this a lot of thought. Your sister mentioned that your brother died a couple of years ago. What was that like for you, experiencing his dying?"

"I know it was peaceful for him, but I don't think it will be like that for me. When I was in my twenties, I fell down an elevator shaft. I know I died—they told me that I had to be resuscitated—and it was awful. It was like being in this dark abyss and I was all alone in that emptiness. They say you see light when you die, but all I saw was the darkest blackness and I was terrified. I remember that I didn't want to be there, so I started crawling. Not literally, but I kept willing myself to crawl out of the darkness. It's hard to describe, but I struggled to get out of the dark and that's all I remember until I woke up later in the hospital."

Here was an insider's view of liminal space—*being alone in the emptiness of the darkest blackness*. I recognized in that moment that I was in the presence of a powerfully sacred story which called for a holy silence.

After a long pause, I continued, "What an amazing story. Larry, it sounds to me like you had a deep spiritual experience. You've been on the other side and it was terrifying for you. I can understand why it's hard for you to hear that others want you to die comfortably."

"I think it was a spiritual experience, but I don't understand it. I would really appreciate it if you could explain it to me." Larry's voice was getting softer, the words coming more slowly, and his drooping

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eyes revealed his fatigue, but he continued. "I don't want to focus on dying. Right now, I am alive and that is what I want to focus on. I wish my family would focus on the present and stop talking about facing the future. I don't think they understand."

We'd covered a lot of territory and although there was much more still to uncover, it was time to let him rest. "You've shared a lot with me. Thank you for being so open. I'm hearing that you'd like to understand what's going on for you on a spiritual level. I don't know if I have an explanation, but I'd like to offer my spiritual companionship to explore this throughout your stay in the hospital. I'm also sensing some frustration with others who are pushing you to consider hospice, so perhaps I can help you sort through that over time as well."

"Yes!" He perked up. "It would really help if you could speak with my sister. I don't feel like she's hearing me."

"I can certainly be with you as you express what you want. You were pretty eloquent with me."

"And I've said all that to her before, but she doesn't listen. She says I'm not being reasonable."

"Well, Larry, this is what I heard you say: that you are fully aware of your prognosis. However, it seems to be too much to handle to think about a future that seems so bleak. I heard you say that all you have is *now* and that is what you want to focus on. Is that right?"

"Yes!" Nodding affirmatively, his eyes closed as he let out a long sigh.

"I imagine that your sister and other family members feel helpless and they want to do something. What could they do for you to support you in the *now*?"

"They can just be with me," he replied. "Keep me from being alone. Help stay in the moment with me." I then asked if he had the energy now to invite Monica into our conversation. He agreed but wanted me to be the one to tell her what he had told me.

As I left the room to retrieve Monica, I felt uncomfortable with Larry's request that I be the conduit of information exchange between them. My goal was to help foster their ability to communicate better

with each other. So, once back in Larry's room and in her presence, I encouraged him to share what he had told me. He started, but I could tell that his fatigue was getting the best of him as his voice grew weaker. I was still ambivalent about how much to chime in, but he'd asked for my help. Rather than speak *for* him, I spoke directly *to* him.

"Larry, I am impressed with how fully present you are with your situation. You know that your prognosis is grim, but right now you are here and alive." I then turned to Monica. "He wants you to know that being alive in the *now* is what he wants to focus on." I paused and looked back at Larry. "Did I capture your thoughts and feelings?"

"Yes." He then addressed his sister, "I just want you to be with me through all of this without the pressure."

With tears streaming down her face, she took his hand. "I can do that, Larry." She then thanked me, saying, "I hadn't seen it like that." She then turned back to her brother. "I hear you."

That was hard work. I left the unit and went downstairs to our chapel and just cried. Crying had become a new normal for me since becoming a chaplain—tears shed for the many patients whose suffering I bore witness to. But at the chapel that day, my tears were for me and my brother. The visit with Larry and Monica touched a tender, not-yet-healed wound that Larry's words—*just be with me through all of this without the pressure*—reopened. I grieved that I had lacked the knowledge and skills of true spiritual companionship at the time my brother was desperately clinging to life and hope—skills that would have allowed me to enter the liminal darkness to meet him where he was.

I visited Larry almost daily over the ensuing days and it was important to him that we spend time for spiritual guidance around death and the dying process. Central to our discussions was revisiting his near-death experience in the elevator shaft. At the time of the accident some forty years earlier, Larry had been estranged from his family, living on the margins, and severely depressed, which he self-medicated through heavy drug use. We explored allegorical meanings of his fall down the shaft and his experience of "the blackest darkness." He struggled at first to see any meaning beyond the literal reportage of the event, but soon wondered if it might have represented

the ultimate expression of the bleakness he'd been going through in his life back then: the loneliness and complete disconnection from his family, who then, as now, meant so much to him. I asked about the will he mustered that brought him back from the dark abyss—what he was crawling toward? He was able to answer immediately: "I was crawling toward love."

Helping Larry explore his dark journey through the elevator shaft provided an opportunity for him to transform his fear of death. Inviting his family to enter the darkness with him—seeking comfort that he would not be there alone—enabled him to find a way to surrender to dying. Larry died nearly three weeks after our first meeting, surrounded by the love of family and friends who kept vigil throughout his hospitalization and, in the end, honored his wish to just be with him in the present.

The art of spiritual companionship through the realm of the liminal can be learned, whether we are accompanying others or attending to our own souls. The first step requires trusting that, in the course of time, the very healing we seek can emerge by our journeying through liminal space, listening attentively to what the liminal seeks to tell us. ◆