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# Welcoming the Stranger to the Land of Cancer:

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WELCOMING THE STRANGER TO THE LAND OF CANCER:  
THE PRACTICE OF DEEP HOSPITALITY IN CANCER CARE

by

Theresa Lever

to

The Faculty of the Graduate College

of

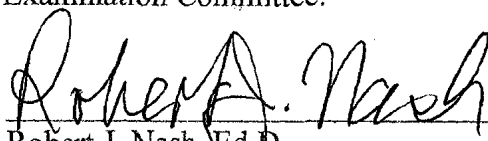
The University of Vermont

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for the Degree of Master of Education  
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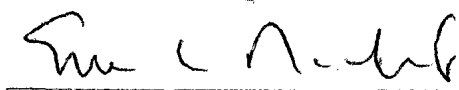
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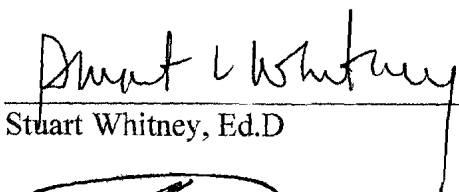
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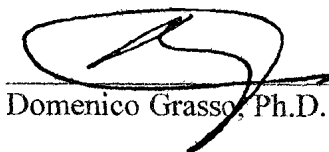
  
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## Abstract

The world of cancer care is a strange land to a person newly diagnosed with cancer. Like someone who leaves the familiarity of home and arrives in a foreign place, the person with cancer loses equilibrium and feels lost, experiences an assault on self-identity, and encounters an alien language and culture. It is this person who knocks as a stranger on the door of *cancerland*. Many philosophic and religious traditions obligate those receiving the stranger to provide a deep hospitality. One model of the practice of deep hospitality is summarized as *door, table, space*. When applied to the relationship between the cancer care provider and the patient/stranger, this hospitality can humanize the experience for both parties and is education in its elemental sense of *drawing out* and *leading forth*—into healing and wisdom.

## Dedication

To Margaret, who would never imagine that a thesis is dedicated to her,  
just as she would never imagine that she is my best teacher.  
I wish her refuge from the storms of life in this world and sweet peace in the next.

## Acknowledgments

All of my experience in the UVM master's program could be described as learning about and practicing hospitality. My independent studies focused on hospitality, and when I shared classrooms with students with diverse backgrounds and opinions I tried to be aware of the opportunities to practice being welcoming, egalitarian, attentive and nonjudgmental. Thus, I gratefully acknowledge each student and teacher who played a part in my learning about hospitality that culminated in this thesis.

Robert Nash deserves my special thanks for two important reasons. First, his Interdisciplinary Studies program itself is a lesson in hospitality. Through it he meets students where they are in life, provides a safe space for expression of their most heartfelt concerns, fears and desires, and affirms and supports their unique meaning-making journeys. Second, his classes are laboratories for the exploration and practice of deep hospitality, beginning with his own love of differences and his request that we all practice *moral conversation*, in which we affirm the “other” and acknowledge our own flaws. I came to UVM determined to learn about deep hospitality, not knowing what a perfect match Robert's person and classes would be. I am deeply appreciative for this surprise gift.

It is a privilege to work with the courageous people who live in the world of cancer, both those with cancer and the care providers. Their stories have been a rich source of my reflection in this study. To protect confidentiality, their names and some minor details have been changed; in all other ways these are their true stories.

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## Chapter One - Refuge

And I feel above me the day-blind stars waiting with their light. For a time I rest  
in the grace of the world, and am free.

—Wendell Berry, *The Peace of Wild Things*

The surgeon had to tell her by telephone because she didn't show up for her office visit. He called to say that the sore place in her arm was cancer. That she would need more surgery, and radiation, and perhaps, depending on the extent of the cancer, chemotherapy. She was struggling to establish some order in her chaotic life, after having lived with her daughter in a homeless shelter, the same child who had been hospitalized for months following an accident that left her disabled. Now, cancer. Did she dread the coming changes? Did she receive the surgeon's words as a death sentence?

I didn't meet Margaret until several months later. I knew nothing about her type of cancer, and was content to leave all the medical cogitation to her doctors. But helping people solve problems and navigate the health care system—that work has my name on it. And Margaret came to me with a cluster of problems and a history of delays in getting her cancer care. I'm still not sure what happened during the six months from surgery to her arrival at the door of our cancer center for radiation therapy, although the number of false starts and missed appointments she had with us provides a clue. Indeed, nine weeks passed from the surgeon's referral to her first kept appointment.

In each encounter she told her tales of woe, and at the beginning everyone was sympathetic. I was working with her—or, more often, without her—to thwart eviction from her apartment, arrange transportation to and from treatments, obtain services for her



almost-wayward daughter, pay her bills and resolve police matters. Situations like Margaret's were the reason Dr. Harold Freeman of Harlem created the concept of a cancer care patient navigator in 1990: to overcome obstacles—cultural, economic and others—so the patient can get lifesaving cancer care when it's needed. Margaret brought me my first real challenge and I thought myself a genius at finding ways to clear every one of her hurdles. Margaret, on the other hand, was a genius at resisting conventional solutions. It wasn't long before the staff started feeling misused, exploited and worn down by her. Money provided for taxi rides was used to buy cigarettes. Her arrival times bore no relationship to her appointment times. She kept her volunteer drivers waiting for hours without apology. She hung around long after her appointment was over, asking to see the doctor again on the busiest days. She was manic and unfocused in conversation, and every solution I offered led to a new problem. She was exasperating and exhausting.

“Imagine how hard it is to be her,” became my mantra. At the time, I was reading Terry Tempest Williams' *Refuge: An Unnatural History of Family and Place*. A naturalist and writer from Utah, Williams endures the cancer deaths of her mother and grandmother at the same time she mourns the loss of a beloved bird refuge to the rising waters of Great Salt Lake. During one visit with her dying mother, she reads aloud Wendell Berry's poem, “The Peace of Wild Things,” in which nature's wildness provides Berry refuge from the worldly fears that keep him awake at night. Reading Williams and Berry, I found an answer to the vexing question of how we could best serve Margaret in light of her refusal or inability to accept ordinary help. Instead of trying to fix everything broken, could we be a refuge from Margaret's worldly concerns? Could we be a

sanctuary for her, a place where she might get respite from the constant pounding of her world on her fragile being? Could the cancer center be a place where Margaret could enjoy the freedom Wendell Berry experienced when in the presence of still water, wood drake and heron? I changed my way of relating to Margaret. I tucked the list of solutions into my back pocket and opened space in myself for receiving Margaret as she was. I made physical space, too, where I invited her to sit with me and talk about whatever she desired.

Margaret's completion of seven weeks of daily radiation treatments felt like nothing short of a miracle. On the last day we invited her to stay a bit longer, to celebrate with pastries and a card of congratulations. She wrote a lovely note of thanks for everyone's skills, care, good humor and patience. After that she called me on occasion to ask for help. One day when she wasn't feeling well and needed her prescriptions taken to the pharmacy, I did so and delivered her medications to her home. I listened while she recited a new litany of very real problems. Upon leaving, I gave her a hug and said, "Margaret, I can't fix much for you, but every once in a while I can pick up your medicine and I can always give you a hug." She told me I was an angel.

I wouldn't be surprised to hear someone use the expression "piece of work" to describe Margaret; that vernacular fits her most salient features. But I prefer to see her differently. In S.L. Wisenberg's memoir, *The Adventures of Cancer Bitch*, the author comments on her tendency to judge people, and adds, "A therapist once suggested that I look at people as works of art."<sup>1</sup> That secondhand advice has been a godsend for me, and lately I've been picturing our cancer center patients as in a gallery. What a dull and

uninspiring gallery it would be if every painting and sculpture evoked the same intellectual and emotional responses! People as works of art is a more descriptive way of saying, “It takes all kinds to make a world,” an expression that reminds me that creation is intended to be wonderfully, surprisingly and even frighteningly diverse. Evangelical leader Richard Mouw invokes a similar concept and image as a way to connect with people who are different. In an interview with Krista Tippett on “Being,” he spoke about people we encounter who are neither kin nor friends.

And what is it that links me to them if it isn’t just a lot of good feelings that I have about people like that? What the Bible teaches is that every human being is created in a divine image. And this means that every human being . . . is a work of art. . . . Seeing other people is a kind of exercise in art appreciation. . . . I come across a person who isn’t just a stranger, but maybe represents a strangeness to me that initially I might feel very alienated from that person, and then to think this is a work of art by the God whom I worship, that God created that person. And it doesn’t come easy. I’m kind of aesthetically deprived, so I have to work at it, but it’s a very important exercise to engage in.<sup>2</sup>

It is my nature to embrace this diversity and to be interested in people who are not like me, although, like Mouw, interest doesn’t automatically translate into acceptance and I, too, often have to work to reduce alienation. It helps that I’m curious about people’s everyday lives; I’m known for asking questions endlessly. I share at least a bit of Mouw’s theology, believing that we each carry within us something of the divine, each equally beloved by the source of creation. I affirm the Christian imperative of welcoming and

offering biblical hospitality to the stranger, the one who is “other.” In my interdisciplinary studies, I took courses that gave me opportunities to ponder the nature of our interactions with the other. An independent study on spiritual hospitality nourished my interest. When I accepted a position in cancer care, I found a favorable environment for an exploration of the practice of deep hospitality with persons diagnosed with cancer.

As an experienced social worker, I’m pretty good at helping people address their problems and access services. But persons with cancer deal with some issues that can’t be “fixed” through social work or medicine. Much of Arthur Frank’s classic *At the Will of the Body* is devoted to this reality. “I reserve the name ‘caregivers’ for the people who are willing to listen to ill persons and to respond to their individual experiences . . . Most medical staff do not have the time to be caregivers, and many may not have the inclination. They provide treatment, which is no less important than caregiving, but it is not at all the same.”<sup>3</sup> About his own experience with cancer, he wrote, “I do not want my questions answered; I want my experiences shared.”<sup>4</sup> His reflections, and those of many others who wrote about their cancer experiences, were an important guide in my learning how practicing hospitality can humanize the experience of cancer patients.

The practice of deep hospitality in cancer care is a perfect subject for the Scholarly Personal Narrative (SPN) writing style. A research-based study may be helpful in proving outcomes—for example, a specific hospitality practice produces particular measurable results. But deep hospitality itself, like SPN, is based on the personal and the narrative. It is highly individual rather than formulaic, and it is ultimately about making room for the guest’s story to be told, acknowledged and affirmed. The multitude of

cancer memoirs teaches us that persons dealing with cancer have a strong need and desire to tell their stories. Paul Stoller, writing about his own cancer experience, came to understand the value of the personal narrative as opposed to the more technical storytelling of his profession.

I began to wonder about my obligations as an anthropologist. Should I continue to try to refine social theory? Should I continue to write “thickly” described stories? Cancer has shifted my sense of priorities. I now believe that the anthropologist’s fundamental obligation is to use her or his repertoire of skills to bear witness. In so doing we are compelled to tell stories about kinship as well as cancer that shed light on social realities. As witnesses to social life, we are obliged to make our stories accessible so that a wide range of readers might discuss and debate what we have written . . . In the end this turn may take us to that elusive and oft forgotten end of scholarship: wisdom, the knowledge that enables us to live well in the world.<sup>5</sup>

Similar to Stoller’s conclusion are Arthur Frank’s comments on witnessing as a vehicle for learning: “The most practical question of all is how we can become productive of ourselves as human beings. We begin by witnessing the suffering of illness, sharing it, and allowing ourselves to live in the light of what that sharing teaches us we can be.”<sup>6</sup>

Writer and sociology researcher Marianne Paget, who died of a cancer called leiomyosarcoma, would have numbered among the fans of SPN.

I am not a detached observer . . . I am an experiencing subject. Furthermore, I love in the same world that I explore. My humanity and my biography enter into

my inquiry as does my specialized training. Phenomenological work involves both the subject's experience and the phenomenologist's experience . . . The subject or subject matter is explored through the subjectivity of the phenomenologist who perceives the subject matter, the phenomena, as a dialectical relation between self-understanding and understanding the other.<sup>7</sup>

Stoller, Frank and Paget are three of a kind, Robert Nash makes a fourth and I'm inclined to join this club of believers in the truth of personal stories. As Rita Charon states in her case for narrative medicine, "Logicoscientific knowledge attempts to illuminate the universally true by transcending the particular; narrative knowledge attempts to illuminate the universally true by revealing the particular."<sup>8</sup>

In the chapters that follow, I explore both the concept and practice of what I refer to as deep hospitality, especially as they relate to cancer care. I probe the religious roots of hospitality and introduce my own framework for understanding deep hospitality: *door, table, space*. My personal experience as a newcomer to the world of cancer serves as a springboard for examining the experience of the patient who reluctantly arrives at the door of what many survivors have called "cancerland."<sup>9</sup> I consider the many ways the patient is like a stranger in a foreign land and apply the *door, table, space* framework to the encounter between the patient/stranger and the native cancer care provider. I comment on boundaries and address the relationship between hospitality and education.

In my brief time as a social worker in the world of cancer, I have not met a single practitioner who has demonstrated lack of caring for patients. Horror stories thrive in the media and through informal grapevines but I have observed only sympathetic concern. It

is my good fortune to come to cancerland at a time when patients' rights are no longer a novelty and humane treatments abound. My reflections on the practice of deep hospitality in cancer care are in no way an indictment of the current state of patient/practitioner relations. Rather, this exploration and its ensuing recommendations are aimed at care providers who believe there is always more that can be done to relieve suffering. Recognizing patients as strangers in need of hospitality and adopting specific deep hospitality practices is one avenue on the journey of humanizing the care of persons with serious illness.

In her bestselling memoir *The Middle Place*, Kelly Corrigan relates her ordeal with breast cancer. Despite having ample financial resources, tremendous support from family and friends, and outstanding medical care, Corrigan experiences her illness as a dismal affliction and her story is crowded with lamentations. She concludes with a commentary on the lavish attention she received from her friends, with whom she expects to enjoy future play dates, parties and celebrations.

It's silly, really, how surprised I was by all the goodness: the cards and e-mails, the dinners and flowers, the book parties and e-mail blasts. I had seen this sort of thing before. In fact, I had seen nothing but this sort of thing growing up on Wooded Lane. I was raised at the knee of a woman who believed in the bottomless potential of the small, compassionate act, a woman whose group of friends practiced—and nearly perfected—the art of camaraderie . . . This essay is for them.<sup>10</sup>

I felt edgy while reading *The Middle Place*, all the time wondering how persons without Corrigan's advantages manage to get through the challenges of cancer. Out of my discomfort emerged affirmation of the special need for hospitality for men and women like Margaret, who are dealing with the ravages of cancer without financial or social capital and who seek refuge from the storms of life. This SPN is for them.



## Chapter 2 – The Spiritual Practice of Hospitality

It is a courageous thing to keep getting up every day, and it is a much more courageous thing to rouse your heart and incline it to love. To care for each other, to open the door to the stranger, to open your heart to the stranger, lifts you up into the great dance of life.

—Father Daniel Homan and Lonni Collins Pratt,

*Radical Hospitality*

As far back as my memory travels, I've had the good fortune to be easygoing and outgoing, curious and concerned about others, with an adequate intellect, without economic disadvantage or physical disability, and with a racial, ethnic and religious identity readily accepted by the majority. Doors open for that kind of person. Growing up in a large family, doing well in school, getting along with friends means I've never had extended periods being a stranger or an outsider. Yet, even those few times of feeling unwelcome—of feeling that people didn't care to know me—still sting.

One incident that somehow stays ridiculously fresh is attending a religious conference on solidarity with Central Americans. I had helped our church establish a relationship with a community in El Salvador and had traveled there several times. I invited my friend Susan, who had been an activist on Central America issues for many years and had accompanied me on one of the trips. Before I knew it, Susan of the keen intellect was hobnobbing with the high-powered people who keynoted the event, and I, without receiving even a superficial welcome, was feeling invisible. Over the years I've tried to make peace with that kind of a closed door. People you've been introduced to

multiple times who don't have a clue that they've met you before. Being at a party where it seems everyone else is engaged in animated conversation, wondering what's wrong with you that no one wants to talk to you. Such snubs can shake a person and as I think about hospitality—welcoming and hearing the story and recognizing the divinity of every stranger—I can only guess at the damage done to persons who commonly experience closed doors. My initial interest in studying the spiritual practice of hospitality grew from the combination of three elements: this concern about who's in and who's out, who gets welcomed and who gets ignored—not only on the personal level but also on the societal level; my natural proclivity to greeting and getting to know people; and a certain Bible study.

A few years ago, during our church's consideration of becoming "Open and Affirming," a phrase referring to the church's way of relating to persons with non-heterosexual orientations, we studied the Bible passages that some use to justify condemnation of homosexuality. We learned that while conservative Christians tend to believe that God punished Sodom and Gomorrah for the sin of sexual activity between men, a liberal interpretation is that God punished the cities for their inhospitable behavior toward strangers. Here's a synopsis: Angels travel to Sodom, where Lot insists they accept hospitality in his home. The men of Sodom demand that Lot turn over his guests to them for sexual exploitation and he replies, "Do nothing to these men, for they have come under the shelter of my roof." By persisting in protecting his guests from harm, Lot's own life is threatened and the angels take action to save him from the violence of the crowd. The next day, God spares Lot and his family when the cities are consumed by

fire.<sup>1</sup> The moral of the story, we were told, is that God commands that we practice hospitality toward strangers. “*Hospitality?*” I questioned. *What is this brand of hospitality that is so significant whole cities are destroyed for lack of it?* I set off to find the answer.

One of my first discoveries was that, despite the Bible being chock-full of hospitality stories, Jews and Christians have no corner on the market of these tales. One from Greco-Roman mythology pairs Jove and Mercury in some mischief-making. The two gods, wanting to have a little fun at the expense of humans one day, disguised themselves as tired travelers seeking refuge. Conjure up an image of strange, bedraggled drifters, and you might sympathize with all those who declined the opportunity to offer food and a place to rest. But, as myth would have it, a poor elderly couple opened their door to the gods, setting before them the best their meagerness could provide. The gods then revealed themselves in a miraculous refilling of the polished off wine. Teaching a valuable life-lesson, Jove and Mercury flooded the homes of those who turned them away and transformed Philemon and Baucis’ home into a temple. Then they granted the couple their wish of being guardians of the temple and dying in the same hour. At the time of their death, they became two trees standing side-by-side.<sup>2</sup>

The Cochiti Indians have a myth with a similar message. When Salt Woman and her grandson traveled to Cochiti (in present-day New Mexico), villagers saw her as a scabby, old woman and refused to feed the two. Little did they know that what they thought were scabs was actually salt. She turned their children into chaparral jay birds, and to the people of Santo Domingo, who welcomed her without judgment, she gave a

piece of her flesh and told them where they could forever find the salt that would make their food taste good.<sup>3</sup>

The original story for Jews and Christians alike is found in Genesis 18.<sup>4</sup> Abraham, recuperating from his recent circumcision, sits at the entrance of his tent on a hot afternoon. When he sees three strangers standing near, neither speaking to nor approaching him, he takes the initiative and runs to greet and bow to them. He offers water for bathing their feet, rest for their bodies and bread for their refreshment. He identifies himself as their servant. He directs Sarah to make cakes, slaughtered a calf, and stands by while they feasted. Abraham asks nothing of them, and any reader would be excused for wondering why he would be so generous toward the traveling strangers. While we might see this as unusual behavior, it was commonplace at the time in the Near East. Because travel was so dangerous there were strict codes regulating the treatment of travelers, whether they be friend or foe. “All sorts of people had to travel at times through ‘enemy territory,’ which meant that hospitality to strangers was a matter of mutual survival. It was a kind of social covenant, an implied commitment to transcend human differences in order to meet common human needs.”<sup>5</sup> The Bible stories, however, communicate that hospitality is not just a matter of survival but also contains in it the possibility of a link to God. Abraham’s unconditional hospitality is rewarded with the amazing news delivered by these messengers of God: his wife Sarah would give birth to a son. “Entertaining angels unawares” is a possibility that Christians have embraced for millennia.<sup>6</sup>

For Christians, the Bible stories about hospitality found in the Hebrew Scriptures are only the beginning. For in the person and parables of Jesus—and later, in the acts of the first Christians—is found the model of hospitality most familiar to Christians. Many gospel stories contain the hospitality theme. An end-time judgment parable has the king dividing the sheep and goats into two groups based on whether they gave food, drink, clothing and welcome to the stranger. With a gesture no less generous and no less damning than those of Jove and Salt Woman, the king rewards the sheep with eternal life and punishes the goats with eternal burning.<sup>7</sup> In Christian theology, we welcome the stranger in part because each person is made in God's image; therefore, in each person resides the Divine. In giving instructions on whom to invite to a dinner, Jesus teaches another lesson on hospitality. Eternal life is yours if you invite the poor, lame and blind to your banquet, rather than your relatives or rich neighbors.<sup>8</sup>

Jesus' ministry as recorded in the Bible is hospitality at its best. He recognizes the humanity of children, women, lepers, tax collectors and others discounted by society. On occasion, as in the story of his encounter with the Samaritan woman at Jacob's well, whom he asks for a drink, he thrills someone by revealing that the person is known to him.<sup>9</sup> Another familiar lesson involves Mary and her sister Martha welcoming Jesus to their home.<sup>10</sup> Martha busies herself with the host's many tasks while Mary sits listening to Jesus. Martha asks Jesus to direct Mary to help her but Jesus replies that Mary has made the right choice. The message is that listening is a more important element of hospitality than a clean house or the right food. In deciding to sit and listen, Mary recognizes that Jesus has something very special to share and makes the space to receive

that gift. In this story, as in the one of Jesus and the woman at the well, Jesus begins as a guest and, in sharing his gift of insight, becomes a host. This interplay of host and guest is a mark of the reciprocity found in true hospitality.

Through the lens of these biblical accounts of hospitality, we might conclude that the songwriter was erroneous when he penned the line, “I’m *just* a poor wayfaring stranger.” While there are many lessons in these tales, one that cannot be overlooked is that wayfaring strangers are not *just* anything. In them the divine is waiting to be revealed to those who would extend a generous, open-handed welcome. The rewards are great, and woe to the ones who would treat the stranger inhospitably. When we hear the term hospitality and think of hotels and restaurants, or when we describe hospitality as the offering of coffee and cookies, we do an injustice to the ancient and venerable meaning of hospitality as welcoming and making space for the stranger without reservation or judgment.

In their book about Benedictine hospitality, Fr. Daniel Homan and Lonnie Collins Pratt affirm the biblical reasons to practice hospitality and offer a more secular and practical reason. “The real question is not how dangerous that stranger is. The real question is how dangerous will I become if I don’t learn to be more open.”<sup>11</sup> Practicing hospitality widens our narrow lives and shatters the delusion that our experience constitutes normality and different ways are wrong and abnormal. On the positive side, “By opening ourselves up to new people, we gain new ideas. We discover the world is filled with people who are nothing like us—and it is a delightful thing.”<sup>12</sup>

Returning to the original question that set me on my exploration—*what is this brand of hospitality that is so significant whole cities are destroyed for lack of it?*—I’ve learned that this kind of hospitality is deep, rich, at once simple and complex, and obligatory in some faith traditions. It can be the cure for hostility, is risky business, is sacramental, is not relegated to religious settings but can be practiced in education, in healthcare, in workplaces—everywhere. I’ve learned, too, that there are endless commentaries on hospitality, from theological, philosophical, sociological, historical and personal perspective. In order to gather and consider the many definitions and concepts, I developed my own image as a framework: *door, table, space*. In the spiritual practice of hospitality, you open the door to the stranger or other, invite the other to your table, and make a space for the other in your life. It sounds simple, but the spiritual practice of hospitality goes much deeper than the commonplace door opening and table setting, and making space for the other is infinitely less innocuous than the phrase suggests.

What follows are brief descriptions of the three stages and introductory comments about making this image real in all our encounters with those who are other. Chapters 7-9 will specifically address how *door, table, space* can be applied in cancer care.

### Door

To open one’s door to the stranger is first to recognize that someone is at the door. When we don’t open the door we are not even acknowledging the presence of fellow humans. Literal and figurative doors that refuse to open are dehumanizing. One only needs to recall a time of difficulty finding a job to get in touch with that experience. When we do open the door, it’s an initial step toward meeting the basic human need of

being known, by communicating what Homan and Pratt call “the core of hospitality: May I know you better? Will you come closer, please?”<sup>13</sup> Which of us does not delight in hearing our name spoken? Or who, in a sea of strangers, has not experienced the thrill of discovering a familiar face and drawn near with a joyful, “We know each other!” A man told me of an experience he had when he had to drive himself to the hospital with something stuck in his throat. Surrounded by strangers in the emergency room, he longed to be in the presence of someone, anyone, who knew him. The stranger at our literal and figurative doors who is in need, who may be suffering, has the same longing. Are you someone who will know me?

A second step concerns the environment into which the stranger is invited. How is welcome communicated? Does the stranger feel included? Does he feel special? Does the host sincerely want to know him? Opening the door is necessary but by itself is no guarantee of the deep welcome that is characteristic of hospitality. Inviting strangers to the table is the next step in the right direction.

### Table

Lynne Westfield, in her book *Dear Sisters: A Womanist Practice of Hospitality*, writes about the formation of an African American Christian women’s book group. At the beginning, the group decided their meetings would not include food like other women’s groups. “We were going to be a ‘thinking’ group.”<sup>14</sup> She describes the first meeting at someone’s home, with only simple beverages served. At the third meeting, the host apologized for providing chips and pretzels and was scolded by the others, who managed to eat all the snacks. In November they agreed to bring only snacks to share for



the holiday gathering in December. Westfield writes, “Our first Christmas ‘snack party’ was a feast of ham, potato salad, collard greens, green beans, candied yams, tossed salad, carrot cake, chocolate cake, and peach pie. Since that momentous communion, we are still sharing a meal at each meeting. The table is set to overflowing with dishes of varied and wonderful descriptions.”<sup>15</sup> Referring to the story of Jesus on the road to Emmaus days after his death, walking and talking with followers who only recognize him after they invite this “stranger” home for a meal and he breaks the bread, she concludes, “Meeting Jesus, then and now, occurs when ordinary strangers, people estranged from themselves and each other, dare to invite each other to the table. What is the aesthetic that breaks into the moment of hospitality that transforms and transcends the stranger-to-stranger relationship? I am suggesting that it is the aesthetic of storytelling and of the breaking of the bread.”<sup>16</sup> She identifies sharing food and stories as sacramental encounters that put us in touch with the mystery of life and connect us to God.

When I invited a group of women to a potluck supper and viewing of the film *Babette’s Feast*, we began with each telling something about herself and it became a moving sharing of each woman’s story over supper. As our time together validated the hypothesis that the storytelling and food sharing elements of hospitality are sacramental, the film validated my image of *door, table, space* as a framework for the practice of hospitality. Babette flees the French civil war and lands as a mysterious stranger in a small Danish village, where she comes to work as the cook for two puritanical sisters. The sisters only take the first step in the practice of hospitality. They open the door but, not inviting Babette to their table or giving her an opening to tell her story, they don’t

recognize her for who she is. The sisters do not open themselves to receive her amazing gift until Babette finally takes the initiative to impart it. When she does, she is recognized as her true self and a whole community is transformed.

Inviting people to a real table for real food can be an act of life-changing hospitality. More often, inviting to the table is a metaphor for the entire practice of hospitality. Homan and Pratt write, “In genuine hospitality, we work to make our entire existence a welcoming table . . .”<sup>17</sup> Hospitality is as much attitude as behavior. When we invite strangers to the table, do we have “us and them” thinking? Do we hosts feel superior to the guests? Do we really have an interest in listening to stories and getting to know people, or do we label their different ways “wrong” and therefore choose to keep our distance? When we sit at the table together, taking a respite from our busywork, we may find it a good place to practice *being* rather than *doing*. This inner work is crucial for the next stage of practicing hospitality—making space.

### Space

Opening the door and inviting to the table are child’s play compared to making space. Making space involves a deep recognition and affirmation of all persons. Greeting is a start, but recognizing and affirming also involves believing that in this stranger resides the divine. Making space also means accepting the stranger on her own terms and not ours. It means inviting the stranger to share his gifts, through participation or storytelling, and not merely be the recipient of ours. In this way there is an ongoing exchange of the roles of host and guest, the reciprocity referred to earlier.

In *Reaching Out: The Three Movements of the Spiritual Life*, Henri Nouwen names the second movement “from hostility to hospitality,” and turns a phrase that has helped me understand what it means to make space for the other: *Poverty makes a good host*.<sup>18</sup> We might immediately think about poverty in the material sense, and, in a way, material poverty does make a good host, because those who have much are often the ones who need locks on their doors, while those who have little are less afraid and therefore more inclined to open their doors. People from wealthy countries who travel to poor countries often comment on the generosity of their impoverished hosts. Undoubtedly, Nouwen experienced this during his time in Latin America and at Toronto’s L’Arche Community of Daybreak for mentally handicapped persons. But when he declares that poverty makes a good host, he is referring to poverty of mind and poverty of heart, and it is the discussion of these that enlightened my understanding of the meaning of making space for the other.

Poverty of mind is the condition of putting aside one’s convictions, opinions and ideas to make space for what one might learn from the other. Who has had the experience of being the guest of a know-it-all host? How hospitably did you feel treated when nothing you offered to the conversation was valued? As Nouwen puts it, “There is no inner space to listen, no openness to discover the gift of the other.”<sup>19</sup> Lest that seem inconsequential—*it’s not the end of the world if my host doesn’t give me the time of day*—consider Nouwen’s insights about a too-full mind.

Well-educated ministers are not individuals who can tell you exactly who God is, where good and evil are and how to travel from this world to the next but people

whose *articulate not-knowing* [emphasis added] makes them free to listen to the voice of God in the words of the people, in the events of the day and in the books containing the life experience of men and women from other places and other times. In short, learned ignorance makes one able to receive the word from others and the Other with great attention.<sup>20</sup>

Along with the marvelous irony of poverty making a good host is the paradox that true wisdom and knowledge come only when we have an articulate not-knowing.

A real-life example can make this less abstract. When I open my door to religious proselytizers—strangers with strange ideas and beliefs—my first inclination is to assume, judge and defend. *They're going to try to impose their wrong beliefs on me and I'm going to stand firm. I'll give them five minutes just to be polite but they're cut off after that. I'll make it clear that I'm as sure of things as they are and they need not visit again.* I might fool myself into thinking this polite approach actually contributes to harmony, and in the short run, I confess, I have inner peace because my ordered world is not disturbed. The identity I desire to keep pure is untainted. But if I can be so guilt-free in cutting off these strangers, what is to keep me from justifying doing the same to any others different from me? Do I really believe it's more dangerous to risk my own sense of security than it is to shut out the word and experience of others?

According to The Rev. Dr. Miroslav Volf, the Director of the Yale Center for Faith and Culture and the Henry B. Wright Professor of Theology at Yale Divinity School, it is a delusion that making space for others will somehow contaminate our purity. His theology of forgiveness and nonviolence was borne of his experience as a

native of war-torn Croatia. Speaking on “Identity and Otherness in a Fractured World,” he described the need for us to welcome, invite, embrace, and make space for the other.<sup>21</sup> He noted that “in times of tension we adopt a logic of purity”—everything that is ours must be pure. But it is false to believe that our identity is pure and exclusive, since “identities are always inhabited by others,” by choice or not. And as our identity is not pure, singular and exclusive, neither is the identity of the other, although we tend to overlook that the other “is one in whom many identities are present.” While we should not be overprotective of what we falsely believe is pure, we do need boundaries. Boundaries are natural and without them there is no identity. Volf proposes having *porous boundaries*, a concept described in Chapter 8.

Henri Nouwen would acknowledge that emptying oneself to make room for others is challenging. We spend a lifetime being encouraged to fill our minds with information, consider ideas and form opinions—and then Nouwen tells us that to be truly hospitable we have to risk being ignorant. Poverty of heart is similar. Where poverty of mind makes space for others’ ideas, knowledge and ways of knowing, poverty of heart makes space for others’ feelings and experiences. As an example, Nouwen points out that faithful people often have certain feelings about God, based entirely on their own experiences. “An inflated heart can make us very intolerant. But when we are willing to detach ourselves from making our own limited experience the criterion for our approach to others, we may be able to see that life is greater than our life, history is greater than our history, experience greater than our experience and God greater than our God. That is the poverty of heart that makes a good host. With poverty of heart we can receive the

experiences of others as a gift to us.”<sup>22</sup> The poverties of heart and mind make space for strangers to retain their otherness, and then to reveal their unique gifts. When we make space in our minds and hearts for otherness, we learn new things and become wiser.

It is in making space for the stranger that the exchange of guest and host roles is most obvious. Interestingly, both the Latin word *hospes* (a root of hospitality) and the Greek word *xenos* mean stranger, guest and host. The ancients recognized this natural role-swap of strangers, hosts and guests. As noted earlier, Jesus often played both guest and host in occasions of hospitality. When a host makes space for the guest-stranger to be her authentic self, the guest has the freedom to offer her particular gift, as Babette finally did when her hosts allowed her to arrange a dinner party. Mireille Rosello, writing about contemporary immigration challenges in France, makes this point succinctly. “If the guest is always the guest, if the host is always the host, something has probably gone very wrong.”<sup>23</sup>

#### Hospitality in health care practice

It is clear that the spiritual practice of hospitality is well-suited to homes and faith communities. It also has important applications in other realms of social life. For example, in *To Know as We Are Known*, Parker Palmer has a chapter entitled “To Teach is to Create a Space,” which is a treasure for anyone exploring how spiritual hospitality can be applied to a learning environment. Chapter 11 of this thesis covers many of the elements of hospitality described by Palmer. Health care is another significant setting for the practice of hospitality and the following introductory remarks provide a foundation for a later discussion about the stranger receiving cancer care.

In *Hospitality to Strangers-Empathy and the Physician-Patient Relationship*, Dorothy Owens specifically addresses physicians, but her analysis is transferable to other health care providers who regularly encounter strangers (patients) in their work. Here we find references to the importance of recognizing in the stranger a person worthy of being heard and of inviting the stranger to reveal his true self by telling his story. The physician cannot do her work without receiving the story. When first in the space occupied by the physician, the patient knows he is a guest, but in the telling of the story, he becomes the host. Owens refers to Martin Buber in describing the creation of a sacred space *between* physician and patient, where empathy in the form of recognizing the other person's suffering occurs. She reassures physicians that in the practice of hospitality, empathy becomes mutual, personal boundaries are maintained and each party remains intact, not subsumed by the other. She suggests that physicians may experience a bonus through this practice. "Hospitality also opens up avenues of discovery of something new and the invitation to view the world from a different perspective. A stranger may not simply challenge but 'transform' the physician through the attention given to the stranger's 'otherness' and may elicit wonder and awe in the presence of the holy, the unfamiliar and the unexpected."<sup>24</sup> At first reading, one wonders if Owens has ever had a doctor's appointment! On reflection, however, it seems right that this is what *can* occur between physician and patient, and I find that this encounter fits the *door, table, space* image. The door is opened when the physician, as host, recognizes the patient's humanity and need for relief from suffering. The patient is invited to the figurative table in the acknowledgement that host and guest each have something to share and are equals in the

relationship. Being equally vulnerable—the patient feeling anxious, fearful and dependent, and the physician aware that she is fallible and that she is not immune to illness and suffering herself—they cautiously make space for each other by putting aside assumptions and prejudices so they may receive what the other has to give.

Nouwen speaks of that space as a place where “healer and patient can reach out to each other as fellow travelers sharing the same broken human condition.”<sup>25</sup> This space is where the healer listens with real attention to the suffering stranger; Nouwen calls listening “one of the highest forms of hospitality.”<sup>26</sup> He is not alone in naming listening as key to the practice of hospitality. Homan and Pratt call it “the core meaning of hospitality,”<sup>27</sup> and as we will see later, Rachel Naomi Remen believes that listening to patients’ stories is a key element to healing.

### Taking steps

In a talk given at Ireland’s Glenstal Abbey, home to Benedictine hospitality, David N. Power, OMI advised budding practitioners to start small and told a marvelous story to which we all should be able to relate. In a supermarket, a young stranger asked Power if he could give her money to buy butter for the family, since she had come up short in paying for the groceries. He was happy to do so but suggested that she buy a less expensive spread so she could get more for the money. She declined, telling him that her family wanted butter and butter was what she would get them. In this simple exchange is found on a small scale the challenge of allowing the stranger to be herself. How many of us would respond to this girl’s need by pressing our own ways of doing things? As Homan and Pratt put it, “Extending hospitality means we give them room to be who they



are, rather than who we want them to be.”<sup>28</sup> Such everyday encounters can be hospitality in action and can also serve as practice for trickier and more demanding situations. Small steps include calling someone by name, sharing food with awareness, and holding our tongues so others can speak, then listening to their stories. These and many other practices can contribute to the creation of living and work spaces that communicate welcome to the stranger. When I moved from working many years at the nursing home to a new position at the cancer center, I found myself a stranger in need of such welcome. The experience, described in the next two chapters, largely influenced my examination of the practice of deep hospitality with persons receiving cancer care.

### Chapter 3 – My Arrival in Cancerland: Integrity and Balance

When I was diagnosed with breast cancer in 1998, I became a tourist in a strange new land. Like most thoughtful and all fearful travelers, I ransacked the library, bookstores, and the web for information. What would I need for a successful journey? Whom could I trust to make the trip with me?

Orel Protopopescu, in “Insulated from Contagion in His Robes,”

*Journal of Medical Humanities*

I do not have cancer. At least as far as I know. I am 57 years old and there hasn't yet been a reason to think “cancer.” The same is true for my five sisters and brothers, ranging in age from 64 to 52, which is amazing because not one of us has what could be called a healthy lifestyle. If there is a heavenly realm of any kind, my mother, who was 84 when she died from complications following a gall bladder attack, is smugly smiling “I told you so. I told you that hearty food would keep you well.” In her mother and housewife heyday, she would boast, “We spend our money on food, not on doctors' bills like the Pitkins,” our much maligned neighbors. Whether it was my childhood diet with its abundance of savory comfort foods, my well-behaved genes or just plain luck, I have not yet had to travel involuntarily to the land of cancer.

Yet I desire to know as best I can the experience of those who find themselves strangers on the doorstep of this harsh foreign land. After working for almost three decades in a nursing home, I am now a social worker in cancerland—the place where cancer and its reluctant hosts live and where cancer care is sought and given. I believe that the practice of deep hospitality can be healing for both the patient-stranger and the

practitioner and can make health care more benevolent and humane. Understanding the experience of the person who has cancer as that of a stranger visiting a strange land—a stranger who involuntarily becomes the guest of medical hosts—can help me practice a hospitality that contributes to healing and wholeness. But how *can* I understand this experience, when all my life I have not only enjoyed good health but also felt like I was one of the “natives” wherever I was?

Never a stranger, until . . .

Here in Vermont people respond disparagingly when I tell them I was born in New Jersey. What they know of the Garden State is ugly oil refineries, crime-ridden cities, the pricey turnpike. Like most of them, I have no idea what gave birth to Jersey’s nickname, since my family moved to Hartford, Connecticut before I could record any horticultural memories. Hartford is my beloved hometown, where I made my first friends, jumped rope and rode my bike on hopscotch-marked sidewalks, sat in the pews of St. Lawrence O’Toole church dreaming of a nun’s life, sledded, skated and swam at the city’s parks, and adopted as second homes the schools where I excelled. In our Hartford backyard we timed our cherry tree climbs so as to deprive the robins of their expected booty. My father grew tomatoes and pitched whiffle balls; my mother dressed and undressed the clothesline a million times, transformed the fruit of our grapevines into sweet jelly, and made sure everyone in our big family had all they needed and then some. I was a friendly kid. I have a memory of accompanying my mother to the grocery store and, from my perch in the cart, saying hello to shoppers in every aisle. She told me that as a tot I did the same in front of our house, interrupting unsuspecting passers-by to

introduce myself and ask them to return the gesture. Although I was not a Hartford native, it was never a strange place; its inhabitants and I were kin from the start.

As it turns out, my Hartford experience was no anomaly. Throughout New England and in travels to other states and other countries, I have been received as if I were one of the locals. Once in the Philippines, while our Filipino host was occupied with business, my friend and I strolled through some blocks of his Manila suburb. We later reported to him that the Valencias two streets down were having a party that afternoon and he replied with amusement that we were more intimate with his community than he. Technically, the Philippines, Hong Kong, El Salvador, Zimbabwe are foreign lands to me, but consider who I am: Euroamerican, English-speaking, white, middle class, educated, mainline and mainstream in so many ways that seem to matter. The power of that social and cultural capital—combined with a natural interest in people and an easy smile—opens doors to red-carpeted receptions. The Artful Dodger’s musical invitation to *Oliver Twist*—“Consider yourself at home. Consider yourself one of the family”—has rung true for me more often than not.

How ironic, then, that where I’m well-known from 30 years of community involvement, here in the organization where I’ve labored loyally for almost three decades and have been considered a leader, here in cancerland not as a patient but as a practitioner, I found myself in the role of stranger.

### Welcome to cancerland

Cancerland, like any foreign territory, can be a strange and inhospitable place to the newcomer. The one who visits cancerland is disoriented by an incomprehensible

language, an unreadable culture, and a sense, reinforced by the natives, that they know everything and he or she nothing. Hence, only the generous hosts have anything to offer and whatever the visitor brings is of no value. They take control and the non-native is merely a beneficiary, at the mercy of others; dependent, if lucky, “on the kindness of strangers.” For the stranger who is also a patient, cancerland holds pain and disfigurement; torture and death; and, worst of all, indifference. If disease doesn’t pluck the life out of its unlucky prey, cancerland itself may do the job. This I know because guests in the alien country of cancer have given copious testimony of its humiliating, frightening and murderous features.

And yet . . . at its best, cancerland breaks out of these wounding restraints. It becomes a place where warm blankets are hemmed with solace and music springs from murmurs of compassion. Paradox is its predominant quality. The weak gain strength and the strong become vulnerable. Wholeness happens not from remaining intact but from being changed. The most intimate affairs take place in the most public regions, and out of this violation solidarity emerges and community grows. Visitors to this cancerland are invited, touched, understood and loved.

I was a stranger who found herself in this strange land. Although I am host rather than guest, circumstances have given me an opportunity to experience some of what the involuntary visitors to cancerland undergo. For twenty-eight years in my previous work I basked in the comfort of being one of the natives, an expert, a member of the family, with all the power and privilege those titles endow. Moving from that position in the nursing home to the new position in cancer care landed me in a place where the landscape,

language, people and expectations were unfamiliar, foreign and harrowing. During my first weeks here, my ego was battered and my stomach rebelled. Tears let loose and self-confidence failed its tests miserably. Anger and bitterness clung to me. But there were also moments of hope, excitement, relief, vindication and pride.

One saving grace of my discomfoting experience is that I am able to use it as a vehicle to better understand how patient-strangers feel when they enter the unfamiliar and dangerous territory of cancer. At the same time I felt wounded, I blessed what was happening to me because it brought me closer to the people I serve—women, men and children who have no choice but to live in the land of cancer. I am acutely aware that my experience does not replicate that of the person with cancer, especially in intensity, endurance and consequence. I use it only as a window to the world of those dealing with cancer, and as a gateway to an exploration of how deep hospitality can be practiced in conventional health care.

As I entered this venture—both the new vocation and the reflection and writing—I chose a tool to help me identify meaning and connect to the spiritual aspects of the enterprise. They are tiny cards (marketed as “angel cards”), each containing a single word intended to inspire, focus or challenge. I selected them randomly, one a week for the first several weeks. Each word became the locus of my reflection on that week’s events, the trigger for personal stories and the spark for my examination of the experience of being a stranger in a strange land. My encounters with these words have been so rich that each has been awarded its own place in these chapters. Although they are discussed separately, I found that they are intimately related to each other and that, despite being selected at

random, each points to an important aspect of the practice of deep hospitality.

### Integrity

Self is whatever story we construct about who we are, depending on whom we are with, and who we would like to be, at any given time. The best way to think about the “self,” then, is as a storyteller who needs to narrate a number of stories in order to create meanings.

—Robert J. Nash, *Liberating Scholarly Writing:*

*The Power of Personal Narrative*

The supermarket-sized Salvation Army thrift store had a ladies’ shoe rack to which I was predictably lured. “I’m always looking for the right sandals,” I told my sister, and my eyes landed on a nearly-new-looking pair of red ones. When I put them on they reminded me of Tara, the young and stylish manager of the radiation oncology center I was just hired into. The image of my feet dressed up to match Tara’s look sealed the purchase.

I’ve been a frumpy dresser my whole life, but my poor fashion sense rarely detracts from my more laudable qualities, which accounted for years of success at my previous workplace. Many excellent candidates applied for my new position, I was told, but I was first choice from the start. With former co-workers lamenting my departure and others cheering my arrival, a swelled head would have been in order. But quite the opposite happened to me. The cancer care program was a new world, and my ignorance about cancer and how to help patients was breathtaking. While the other members of the team were oozing excitement and confidence, I felt like a stranger in a strange land, with

everyone around me speaking a foreign language. During my first week I had knots in my belly and lots of dreams. In one I was pleading, multiple times, for someone to call 911. After being the knowledgeable, go-to person for decades, I was feeling dim-witted and even fraudulent.

The first card I chose was INTEGRITY. Driving to work, my red sandaled-feet exercising the gas and brake pedals, I thought about two meanings of integrity: to be honest and true to oneself; and to be whole, unbroken. Integrity occupied my mind when I entered the conference room to join my new team for its second meeting.

Even before making my selection that morning, I was aware that I was struggling with how to present myself to the group. In the first team meeting I was subdued—not at all like the me I know and love—because I was feeling second-rate. I knew it didn't feel right, but I thought that to be bold, friendly and talkative would have conveyed a false message that I had it all together. During this second meeting, though, I was like Judy Garland's Dorothy, my confidence and power enhanced by fancy footwear.

Everything was going just peachy, when halfway through the meeting I left to answer a page. As soon as the conference room door closed behind me, my red sandal broke! The shoe I wore to be more like Tara when I thought I couldn't be just myself had lost its integrity! I laughed for the rest of the day and evening at the gentle message. The Nash quote that opens this section, and his reference to “changing personal narratives,” were balms for my wounded identity.<sup>1</sup> It affirms that my integrity is not tied to my one true “self,” but to my multiple true “selves,” each with its own context-rich



story. Having integrity—being whole, undamaged, and true to myself—does not shackle me to a single, fixed or unambiguous self-definition.

I wrote in my journal, *We are more than one thing. When our one thing we think we are gets disturbed, or changes into something else, we might feel that our integrity has been attacked, but we can still be whole, just different than we expected. Is the Theresa who is smart, bold and outgoing the only thing I am? Or is there an okay and real Theresa who is less knowing and more receptive, cautious and humble? And applying this awareness to my new work in cancer care, I wondered, For a person with cancer, is it possible to view oneself as different but still whole? Being changed is different from being broken. In fact, being unchanged is impossible.*

The common use of the word integrity is to describe a state of being intact, but there is an intriguing meaning that derives from its Latin roots: in (not) and tangere (to touch)—untouched. This literal definition is unreasonable since it is not possible to live in this world and remain untouched. It is also provocative when considering it in the context of the patient as a stranger in the land of medicine. Most of us desire to have some control over the ways we are touched and by what or whom, but patients lose that privilege. They are touched by cold and incomprehensible machines, by many hands on bare flesh, by medications that are equal parts antidote and poison. They are even “touched” by the uninvited intervention of a social worker.

How does a patient-stranger maintain her integrity when cancer has broken his body; when he has to submit to myriad unwelcome touches; and when the humility of being a patient makes him unrecognizable to himself? If one’s sense of integrity ensues

from feeling whole, untouched, and self-confident, then the experience of being a patient-stranger is tailor-made to violate that sense. But if a person can recognize that he is more than one thing, for example, more than a person in excellent health, more than someone accomplished in his particular field, he will be able to withstand the identity-threatening winds of serious illness. A patient who embraces the concept of multiple selves is able to preserve a sense of integrity by narrating the diverse stories of her health and illnesses, her achievements and disappointments. College drop-out, bronze-medalist, vegetarian, yoga instructor, *patient*. Mother, retiree, spiritual guide, divorcee, *cancer host*. All are authentic identities that make us more complicated than we typically appreciate. Physician, teacher and storyteller Rachel Naomi Remen affirms this reality. “Wholeness includes all of our wounds. It includes all of our vulnerabilities . . . Integrity simply means what is true, to live from the place in you that has the greatest truth. And that truth is always evolving as well.”<sup>2</sup>

And now my turn: grandmother, singer, lay pastor, humbled cancer-worker, bold red sandal-wearer! No doubt about it—those sandals really *are* me, even if I had mixed motives in buying them. Integrity has me in her clutches, and I have been glad for her companionship on this intriguing, risky journey through cancerland.

### Balance

‘Tis the gift to be simple, ‘tis the gift to be free,  
‘tis the gift to come down where we ought to be.  
And when we find ourselves in the place just right,  
‘twill be in the valley of love and delight.

—Elder Joseph Brackett, Jr., “Simple Gifts”

I cried at work one day, and I thought of my friend Michiko, who had cried at work a couple of weeks earlier. Over the previous weeks I’d thought of her a lot, my homesick Japanese friend, as I reflected on how it feels to be a stranger in a strange land. She was in my heart when I felt the sting of being silenced several times by a new co-worker who jumped at the opportunities to tell me and everyone else that I was asking unnecessary questions. Michiko’s name was written on the disappointment I felt at having no phone number assigned and being left off the team roster. Her words, “That’s how I feel every day”—the words of someone who is not at home in this land—pierced my ears.

The indignities compounded. My security card proved to be a dud in getting the doors open (locked out of my own workplace!) and the promise of getting one of the unclaimed offices, dangled before me a week earlier, was snatched away. Within two weeks of my hire, the radiation oncology manager, nurse and doctor asked a vice-president for a meeting to register their concerns about me. I was not invited but heard the dispiriting story a day later from my supervisor, who had sat in the hot seat. The meeting opened with, “Theresa has overstepped her bounds.” My supervisor recounted that they became tongue-tied when she asked for specifics but I knew everything I had said and done that disturbed them. I had advocated for a public open house rather than just one for dignitaries, suggesting that we take advantage of the excitement and support of the community, which had been waiting decades for the radiation treatment program. I crossed a line when I said that, like the nurse, doctor and therapist, I hoped to meet every

new patient, to introduce myself and my services. I asked, “What will be the first thing a patient will see and hear upon entering the building?” And I’m certain I offended someone when I suggested there might be a difference between interviewing a patient with pen and paper and interviewing with eyes on a computer monitor. When my supervisor, a social worker herself, defended me by emphasizing that these are the kinds of issues a social worker addresses, the VP pointed to the others in the room and said, “These are my experts. I stand behind them one-hundred percent.”

I learned what it is like to find oneself in a land of experts—experts at the language and the culture; technical experts; experts with knowledge that is somehow deemed, in their eyes and, increasingly, in yours, more significant than any knowledge you possess. Is this how the power of expertise was meant to be wielded? I felt oppressed and powerless to challenge my oppressors, sad and lonely and broken, and yet . . . I am grateful for the experience because it helped me know a little of what some patients might feel in cancerland.

During this period I half-expected my next word to be “silence” or “freedom.” Instead, in the weekly ritual my husband and I had quickly established, I selected BALANCE. Balance! I have always valued zeal and passion. Why keep the see-saw in the middle when you can have the fun of soaring and bumping? Disappointed, but trusting in the process, I left for work. When I pulled into the parking space, I was listening to a National Public Radio story about the new conductor of the New York Philharmonic, who surprised everyone when he chose a singer to be the orchestra’s artist-

in-residence. The story continued with baritone Thomas Hampson in the background singing “Simple Gifts,” with its line, “And when we find ourselves in the place just right . . .” Balance! Balance is about finding the place just right! I had recently studied the “Simple Gifts” lyrics while creating a worship service based on the song’s themes, and I had concluded that “the place just right” is a place of humility. Joseph Brackett’s images of coming down from a high place, and his “to bow and to bend we shan’t be ashamed” led me to this interpretation. When Thomas Hamson crooned, “’Twill be in the valley of love and delight,” I heard it as a call to reflect on the balance that is achieved through humility. How was humility—or its opposite, pride and self-importance—manifesting itself in my struggle at work? Was my sense of being off-balance somehow related to a lack of humility? Was I feeling abused and bruised because in my desire to soar I’d actually fallen off the see-saw from its highest point?

My writing during this time records my surprise at how outside forces could throw me off balance so easily. I noted that being off balance affected my productivity, zapped my energy and half-paralyzed me. I also observed that “the place just right” is on the ground. The rare person can balance well on a beam; rarer still is the one who can balance on a high wire. Most of us achieve balance when our feet are on the ground. Reflecting on the connection between balance and humility, I became aware that I often want to be “on top,” to stand out in a crowd, to be a star. Parker Palmer invoked a related image when speaking about a time he was suffering from depression.

I finally learned, with the help of this therapist, that depression didn’t need to be pictured as the hand of an enemy trying to crush me, but rather the hand of a

friend trying to press me down to ground on which it was safe to stand. And through that realization, I understood that part of what took me into depression was that I was living life at artificial heights, at untenable elevations, so that the elevation involving a kind of inflated ego or a free-floating spirituality or a detached sense of “oughts” and in that sense a false ethic, or simply living intellectually in my head more than in my feelings and in my body that all of those things put you at such altitude that if you trip and fall, which you’re inevitably going to do . . .<sup>3</sup>

Weeks later, distanced from the suffering of those early days, I wondered about my own role in the painful drama. Perhaps if I had approached my new position and my new team with less boldness and more humility I would have had a more successful start. What would that have looked like? For years I taught nursing assistants that when caring for the elders at our nursing home, their approach should not be based solely on their own personalities but rather on what the elder needs and desires. In my new position, I proved to be deaf to my own lesson. I was so focused on my need to be held in high esteem as a valued contributor that I neglected to discern what the situation and the team needed. I could have listened more instead of jumping in with new ideas, nodded affirmation instead of questioning, and focused on observation rather than participation. These acts would have kept me closer to the ground and less vulnerable to being thrown off balance.

Humility is tricky. When it is voluntary, it’s a virtue. But when it is involuntary, it can be felt as oppression. More from my journal: *Well, I sure did feel humbled today, but not of my own doing. Sitting with the team, wanting to speak and feeling that I’d be*

*stomped on if I did. I feel so subservient! Everyone else seems to act freely but I'm constrained.*

Jean Vanier, the founder of the L'Arche communities who has worked for decades with people who have mental disabilities, has considered this issue of forced humility. He links balance and power and uses an image of being *pushed* down, rather than the image of a person freely *coming* down from a higher place.

The balance of our world frequently is seen as a question of power. . . . When you have power, we can very quickly push people down. I'm the one that knows and you don't know, and I'm strong and I'm powerful, I have the knowledge. And this is the history of humanity<sup>4</sup>

This “pushing-down” power is commonly used by health care professionals who have knowledge they believe their patients need. Even when this use of power is an unintentional consequence of the application of specialized knowledge and skill, it can easily be felt by the patient as oppression and humiliation. It is a challenge for the practitioner to use her knowledge in a way that does not create this sense of oppression and an equal challenge for the patient to practice self-determination while acknowledging that he may need what the practitioner is offering. Parker Palmer asserts that balance is achieved not through humility alone but through the “creative tension” between belief in the truth of others and belief in our own. “The two in tension help us to know when to listen and when to speak, when to accept and when to resist, when to yield to the tugging of the communal bond and when to tug back.”<sup>5</sup> When I practice humility, it's not all about me, but neither is it complete acquiescence to the other.

A patient-stranger enters cancer care's alien territory wanting to feel and be perceived as a person of significance. A person who is in control of his or her own life, not someone at the mercy of others. In reality, the patient is *not* in total control and benefits from the mercy of the community of healers. Like me in my humbling situation, the patient who wants to enjoy a sense of balance needs to seek a middle ground, a place where the person's own knowledge and ignorance are complemented by the ignorance and knowledge of the healers. The healer who seeks balance must do the same.

"I'm not used to taking. It's not like me." She is my age. She was finishing up her breast cancer treatment. The ordeal took her hair, her composure, and her financial security. She stays awake at night worrying about debts and how she will manage paying for food and the rent. When I gave her the Thanksgiving basket the cancer center team made up for her, she hugged me. She expressed her deep gratitude. And she said, "It's not like me to take." Perhaps since being diagnosed with cancer she has come to realize that she has multiple authentic identities. Hopefully she can see that one of those involves being on the ground where she can receive from others.



## Chapter 4 – Kindness, Presence and Respect

An essential goal in humane primary health care is to strive constantly toward loving kindness for the benefit of ourselves, our patients, and, indeed, all sentient beings. —Steven K.H. Aung, M.D.

### Kindness

My mother spent 40 days dying. My father, her 83-year-old husband of 60 years, was her companion each of those hospital-weary days. For half of that time, they were 90 miles from home and Dad had to stay overnights in a hotel. Each evening, the desk clerk greeted him with some version of “How did things go today, Mr. Purcell?” Dad was exhausted, he was starting to limp for no apparent reason, and his heart was breaking. When he told me about the desk clerk’s interest, it struck me that simple kindness was carrying him through the ordeal. I have never stopped thinking of how that small act of kindness saved him.

Reflecting on this event and others recorded in this chapter, I am impressed by how easily kindness can change the course of a patient-stranger’s journey. Physician Steven Aung recounts a private session with The Dalai Lama, during which Aung asked about the difference between Buddhist medicine and Western medicine. “The holy man replied that Buddhist primary care physicians must always provide a blessing as part of their diagnostic and treatment protocol.”<sup>1</sup> Along with treatment, the Buddhist physician “will also bless the patient quietly or silently with metta” (loving kindness). Aung describes the lifelong process of learning the practice of metta, then adds that non-Buddhist physicians can become more humane practitioners through other methods, such

as “cultivating a more positive attitude toward their patients, smiling at them, wishing them well, listening to them . . .” A blessing, smiling, well-wishing, listening—such small actions! Like the hotel clerk’s greeting, these modest deeds of kindness take little time, cost nothing, and, with the exception of attentive listening, require no special skills. Yet they have the potential to transform a foreign land into a welcome home for the distressed and battered stranger.

In the first weeks of my new work, such actions were noticeably absent. There was one outstanding exception to this unfortunate rule. Every time Claudia saw me, she would greet me in a voice sweet and sincere. The few times we exchanged e-mails on work matters, she wrote, “Thank you for all you do, Theresa.” By the measures of math and literature, her words amounted to almost nothing, but they were a priceless salve to this stranger in need of welcome. I don’t care that the exhortation to practice “random acts of kindness” has become cliché; I believe that both random and planned acts of kindness are powerful medicine for healing persons and mending a broken world.

Indeed, the presence and absence of kindness is a theme in illness-related writings. In her poem “Kindness,” Naomi Shihab Nye proposes that you can’t know kindness until you’ve lost something valuable, until you know deep sorrow.<sup>2</sup> “Then it is only kindness that makes sense anymore / only kindness that ties your shoes / and sends you out into the day to mail letters and / purchase bread, / only kindness that raises its head / from the crowd of the world to say it is I you have been looking for, / and then goes with you every where / like a shadow or a friend.”

What a life-saving image! Kindness personified, telling the sorrowful one, “It is I you have been looking for.” Kindness, who, once found, becomes a constant companion. Is it possible for the providers of cancer treatment to be purveyors of that species of kindness to the patient-stranger? Yes, it has to be! But it doesn’t happen automatically; it’s not just common sense as one might expect. It is a part of the conscious practice of deep hospitality in medicine.

Kindness can also bring beauty to a beastly situation. The Irish poet and philosopher John O’Donohue named “the faces of those I love” and “beautiful landscapes” as what came to his mind when he heard the word “beauty.”<sup>3</sup> Next on his list was this: “Then I think of acts of such lovely kindness that have been done to me, by people that cared for me, in bleak unsheltered times or when I needed to be loved and minded.” There can be much ugliness in disease and its treatments, in affliction and deterioration. How is it possible that there could be beauty in the plight of a patient whose survival is uncertain or one whose illness has wrought disability or deformity? Kindness is the hero to the rescue; kindness adorns and graces that which is ugly while it inspires and consoles the sufferer.

A month after my mother’s death, my father drove the 90 miles back to Savannah for his own medical appointment. While there, he called the hospital to ask my mother’s former care manager if he could treat her to lunch. Like the hotel desk clerk, Carola had reached out to my father with kindness. She is a competent professional, but more than that she is a wise woman who understands how far a little kindness can go in healing wounds of the heart. During the two weeks my mother was her patient, Carola had

spoken to my father in warm, sympathetic tones; she had placed her hand on his arm, looked into his face, listened to him, and responded to his distress. How interesting that the word “kind” comes from the old English word for natural, native, innate, *with the feeling of relatives for each other*. To treat a patient-stranger kindly, then, is to treat the person as kin. I’m sure my father felt a kinship with Carola during those rough weeks; had Thanksgiving not already passed, no doubt he would have invited her to celebrate with the family!

Part of the magnificence of kindness is that it isn’t bound by person, place or time; it can be practiced by anyone, anywhere, in any moment. When cancer survivor Lorraine Ryan spent seven weeks in a hospital following a bone marrow transplant, doctors would check in briefly, “but this sweet man, Juan, was one of the few people who was genuinely interested, who showed he really cared.”<sup>4</sup> Her poem “Finding God at Montefiore Hospital” reveals that the source of the kindness that helped her survive and heal was the housekeeper who mopped her floor at night. “With every move, he looked up / “How’s it really going?” / “Did your boy come up today?” / “How is he doing without you at home?” / Sometimes when I couldn’t lift my head /off the pillow—/ when vomiting and mouth sores/wouldn’t let me speak—/ the swish of his mop / bestowed the final blessing / of the night.”

### Presence

The surgeon met us in a busy and narrow corridor just off the main lobby. There, opposite the cashier’s office, he gave us the bad news . . . and rushed off. His abruptness was so unnerving we could hardly absorb the diagnosis.

It is perhaps overly dramatic to say that chocolate cream pie rescued me from a state of nonexistence. It may be more honest to say that everything-from-scratch baking saved me from irrelevance.

The choice of the word PRESENCE prompted me to consider my dismay over not being permitted to be present in the cancer care program in the way I expected. I counted on being a full member of the team, bringing my particular knowledge and skills to the holistic treatment of patients with cancer. Locked out of this role by the “experts,” with limited access to the cancer center, I had to rethink how I might be present to what was happening there. My opportunity came when my baking talents met the team’s need for nurture. The day I brought in two chocolate cream pies for Marty’s birthday celebration, he jumped up, shouted, “You’re my best friend! I love you!” and gave me a big hug. In the three weeks we’d known each other, he hadn’t given me the time of day. The pie had unlocked the door to his heart—albeit temporarily and on a small scale. I basked in this small victory of presence—being present in a way I hadn’t planned on but which turned out to be just what the doctor ordered for my stressed co-workers. How silly it seems now, but how important at the time!

What hope does the stranger entering cancerland have for her own presence there? How does the reality match her expectation? Barbara Ehrenrich, writing in *Harper’s Magazine* about her experience with breast cancer, describes waking up after a surgical biopsy under general anesthesia.

I awake to find him [the surgeon] standing perpendicular to me, at the far end of

the gurney, down near my feet, stating gravely, ‘Unfortunately, there is a cancer.’ It takes me all the rest of that drug-addled day to decide that the most heinous thing about that sentence is not the presence of cancer but the absence of me—for I, Barbara, do not enter into it even as a location, a geographical reference point. Where I once was—not a commanding presence perhaps but nonetheless a standard assemblage of flesh and words and gesture—‘there is a cancer.’ I have been replaced by it, is the surgeon’s implication. This is what I am now, medically speaking.<sup>5</sup>

Ehrenrich rails about the blurring of “the line between selfhood and thing-hood, me and it.” The patient-stranger entering the land of the native “experts” generally cannot define the terms of her presence. Ehrenrich wants to be present as the person she defines as “me,” but feels pressure from medical personnel and loved ones, to accept that as long as there’s a cancer to eradicate, “it” usurps “me.” Ehrenrich is not alone in making such observations. It is an unusual practitioner who invites the patient-stranger to determine for herself the nature and dimensions of her presence.

In *Kitchen Table Wisdom*, Rachel Naomi Remen writes about a man who had lived for many years as a refugee from communist East Germany and was now living with cancer.

For some time Dieter had suspected that the chemotherapy was no longer helping him. Convinced at last of this, he spoke to his doctor and suggested that the treatments be stopped. He asked if he could come every week just to talk. His doctor responded abruptly, “If you refuse chemotherapy, there’s nothing more I

can do for you.” And so Dieter had continued to take the weekly injection in order to have those few moments of connection and understanding with his doctor. The [support] group of people with cancer listened intently. There was another silence. Then Dieter said softly, “My doctor’s love is as important to me as his chemotherapy, but he doesn’t know.”<sup>6</sup>

Like me, Dieter had no license to determine the manner of his own presence. He wanted to be present not as a patient receiving treatment but as a suffering human connecting with another human who cares. Lamentably, he did not have the liberty to create or even revise the rules. But, like me, he created a way to be present—imperfect, but far better than absence or nonexistence.

A wonderful paradox is that one potent way we can affirm the presence of the patient-stranger is through our own presence, when we practice attentive listening. This is a common theme in the writings, advice and practice of those who embrace deep hospitality and is discussed at length in Chapter 9. Homan and Pratt frequently refer to the value of presence and listening. Asserting that people who are suffering need only our attentive presence, they add, “Hospitality is a way to counter the thousands of times another human being has felt less than human because others didn’t listen.”<sup>7</sup> Stan Mack’s description of receiving the bad news of his wife’s cancer from a rushed doctor in a busy hospital corridor is both ghastly and entirely believable. Dr. Remen teaches medical students that presence, listening and witnessing make powerful medicine.

Certified poetry therapist and author John Fox, in his poem “When Someone Deeply Listens To You,” writes, “When someone deeply listens to you / your bare feet

are on the earth / and a beloved land that seemed distant / is now at home within you.”<sup>8</sup>

By deeply listening to the homesick stranger who finds himself in a foreign land, we create a sense of home. Home is where you are no longer a stranger because someone has listened deeply to you. This is a virtuous environment we so often fail to create in our homes and close-knit communities. Can we hope to make such a “home” for patients and practitioners in health care? Where healers are under pressure to “do” because “doing” is billable but listening is not.

On the way to work the morning I chose the “presence” card, I thought of a prayer that contains the line “May you trust that you are exactly where you are meant to be.” I took heart in this notion, and felt it meant that I needed to continue to find ways to be present in my challenging situation. But such a feeling is a luxury, because I’m not really a stranger and I don’t have cancer. How does the person with cancer, the real stranger to cancerland, hear this prayer? Opening the door to our cancer center, can that person possibly be thinking, “This is exactly where I’m meant to be”?

### Respect

You will stroll right past him if you aren’t careful. Instead, look closer, look in the person’s eyes, search for that spark of light, and let yourself be open to the possibility of God coming to you in the stranger . . . Here is the core of hospitality: May I know you better? Will you come closer, please?

—Fr. Daniel Homan and Lonni Collins Pratt,

*Radical Hospitality*



I was using the cancer center waiting room as a throughway, when I decided to give more than a nod to the folks raising their heads from their magazines whenever the swish of a passer-by caught their attention. I turned around to find the eyes of a man and woman on me and I approached them with a smile and a “How are you today?” I quickly discovered that they were charmingly odd, the kind of people you might avoid if hospitality were not your thing. The man took my name tag in his hand and said, “I knew someone named Theresa. She was my wife.” He proceeded to tell me a tragic love story. She said she was going to marry him as soon as she graduated from high school and, to his surprise, they tied the knot the day after graduation. Soon afterwards she was diagnosed with a blood cancer. The doctor said there was nothing he could do for her and commended her to the care of her young husband. She was nineteen when she died. “She wanted to die at home and so I kept her there,” he said, wiping his eyes with a handkerchief retrieved from a ripped pocket. His sorrow was a half-century old. If I had breezed through the waiting room that morning, giving everyone the usual cursory glance and smile, I’d have missed this story. I’d have missed the chance to connect, via an old lover’s tears, to a namesake from a time gone-by. I’d have missed the chance to elicit a poignant memory both aged and fresh, and to express my admiration and appreciation.

Turning back to give a second look at this couple created a rich experience out of what might have been only a superficial encounter. The word “respect” literally means “look back at” or “look again,” from the Latin *respectus*—*re* (back, again) and *specere* (look). Anyone who has trouble giving life to the abstract “respect” should dabble in this image of taking a second look at someone. To invest a second look is to acknowledge the

person's worth. I respect someone when I take a good, close, second look at the real person. Not just passing by, but passing by and then looking back. Hmm . . . that person is worth a second look!

Am *I* someone worth taking a second look at? There were times in my first weeks in the cancer program that I felt people didn't think I was worth a *first* look! I felt that there was no curiosity about me, no interest shown in my experience or in me as a person. It doesn't take many such experiences to whittle away self-esteem, eventually causing the person to question her own value. If this happened to me in my own "native land," how much more severe is it for the patient-stranger? Persons who have cancer have already suffered assaults on their self-view. Like any patients on their first visits to medical offices, they feel out of their element, fearful and vulnerable. What happens when they approach a desk and the receptionist's head stays lowered? When the nurse taking the medical history has eyes glued to the computer screen? When people rush by without even a flash of recognition, allured by something in the distance rather than being aware of what is right in front of them?

Jean Vanier, speaking about his experiences living and working with mentally disabled persons, assigns tremendous meaning to being seen. "The deepest desire for us all is to be appreciated, to be loved, to be seen as somebody of value."<sup>9</sup> When describing "respect," the references to sight are not merely symbolic. Whether and how we actually look at someone, actually meet their eyes, is a measure of the respect every person desires. Buddhist monk Thich Nhat Hanh makes this point and adds that it benefits both parties. "When you practice looking at people with the eyes of compassion, that kind of

practice will become a good habit. And you are capable of looking at the people in such a way that you can see the suffering, the difficulties. And if you can see, then compassion will naturally flow from your heart. It's for your sake, and that is for their sake also.”<sup>10</sup>

Several studies have focused on what respect from physicians means to their patients. A 2006 report from Johns Hopkins University School of Medicine notes, “In the discourse of medical ethics, respect is commonly manifested by the protection of patient autonomy . . . by providing information to patients about their treatment and involving them in making decisions about their care.”<sup>11</sup> I believe that the respect that contributes to the patient-stranger's sense of wholeness goes beyond this limited definition. Workers in the world of medicine would do themselves and their patients a favor to adopt the “look back at” meaning of respect.

I met a man at the cancer center who was the sort of fellow who might not attract many second looks. He had an old, sad-sack appearance, with sagging shoulders and a couple-of-days-old beard. He and his daughter were both quiet and unassuming. I was there to help him execute an advance directive, but he was feeling lousy so I told him it was fine to put it off for a while. We continued to sit together—he, his daughter and I. He told me that the diagnosis of esophageal cancer a month ago came as a big surprise. Because his radiation treatment will affect his ability to swallow he has a feeding tube in his belly. It was 2:30 in the afternoon and he hadn't eaten anything yet because he felt full. He was having more trouble swallowing but was also having a problem pouring the food into the tube. He wasn't expecting miracles. There was little I could say or do.

What I gave him was a second look, space to tell his story and my presence with his suffering.

“One of the most important ways of extending hospitality is to quietly companion the person who is going through some awful thing.”<sup>12</sup> In order to be that companion you must not be distracted by something more important or more appealing. You must notice, look back, look again, respect.

The memories of my first weeks in the new position are now dim. A year has passed since those early days that felt so dangerous, disconcerting and disheartening. Was it really that horrible? My journal and my husband, who consoled me through his steady presence, are my witnesses. My supervisor also remembers the high emotion and how she felt as discouraged and sad as I. She recalls, too, how each of our meetings ended with me saying, “But it’s okay. It’s giving me a lot to write about,” and the laughter that comment always engendered. The patients rave about the kindness at the cancer center. The staff are glad to see me come around and the feeling is mutual. At team meetings, I’m quieter than I am with other work groups, but I pipe up when appropriate. The lessons on integrity, presence and balance have been particularly valuable in helping me find my way.

How would things have gone for me, the stranger in cancerland, if someone had practiced hospitality toward me? How different could any patient’s experience be if deep hospitality were practiced where they receive their care? My own experience was a springboard to explore whether and how my *door, table, space* framework for hospitality can be applied in a conventional health care setting.

While the nature of our encounters with persons who are strangers is my passion, it is my tendency, after exploring concepts such as kindness and respect, to question the value of such examination. Is it all fluff? Am I saying anything of any import? I am heartened by counting as allies the many healers, educators, philosophers and writers who find these concepts to be crucial in the ongoing building of a humanistic world. Robert Nash's words in an SPN class encouraged me as well. "Be open to everything in the other's story. Identify overlaps because overlaps bind us. This leads us to living peacefully." Such a laudable goal is worth pursuing.

Cancerland may sound like a fictitious locale, but it is the very real world, a place of enormous need and opportunity where patients' narratives often produce both inspiration and paralysis. "It is the greatest of all mistakes to do nothing because you can only do little—do what you can," is the Sydney Smith version of a well-traveled quote.<sup>13</sup> This counsel has served me well in the land of cancer. One woman came to me to talk about her insurance coverage. She had breast cancer and surgery five years ago; radiation was recommended but she couldn't face driving to Burlington every day for several weeks. Each year she has had a recurrence of her cancer and was finally accepting radiation treatment now that it is close to home. She was disabled from other medical problems prior to having cancer and is married to a disabled man who has been incarcerated for three years. When he was jailed, the household, which was already robbing Peter to pay Paul, lost his monthly disability payment. She sends him money from her check for phone calls and the canteen at his Kentucky jail. She misses him and laments that his release may be delayed because of an attorney's error. She is hounded by

debtors; her car is starting to act up; she went three weeks without vital medications because she was broke. She has multiple physical and psychiatric diagnoses and, of course, cancer. At our first meeting she was shaking. She said it was because she had just come from the credit union where she learned that a check she post-dated had been accidentally deposited. The mistake caused her to be in the red, creating one large overdraft charge and smaller ones every day until the deposit of her next disability payment.

Listen, and breathe. Then do whatever small thing you can. Out of our department's petty cash fund I loaned her the amount she needed to stop the daily negative balance charges. She told me it was a blessing from God.

A far cry from fluff.

My brief sojourn as a stranger in cancerland was one of the guides at the beginning of this exploration of deep hospitality practice in cancer care. Words were another. When I moved these words from the abstract to the concrete, applying them not only to my own experience but also to that of the patient-stranger, they helped me envision a hospitable health care community. One where both practitioners and patients can maintain their sense of wholeness because no one has to be tied to a single unshakable identity, where the roles of guest and host, patients and healers are fluid. I can imagine a place where people are grounded, not because someone pushed them down but because they understand their shared human frailty and their personal limitations and vulnerabilities and because they are considerate of the needs of others. Where each is given the freedom to decide the terms of his and her presence, and each is present to the

other through attentive listening. It is an environment of healing where everyone is seen as worthy of the respect of a second look, even the irascible patient and the noncompliant one, even the doctor who delivers bad news in a crowded hallway and the social worker who rushes in and out. Where kindness is always in abundance, even when cure is in short supply.

This chapter opens with an epigraph by a breast cancer survivor who wrote a poem entitled “Return to Cancerland.”<sup>14</sup> Orel Protopopescu remembers that on her first trip to cancerland she wondered, “Whom could I trust to make the trip with me?” The answer is *healers*, who, by practicing deep hospitality, respond not with fear or indifference but with delight and welcome, when the patient-stranger knocks at the door.

## Chapter 5 – The Patient-Stranger

Your relationships, your work, your sense of who you are and who you might become, your sense of what life is and ought to be—these all change, and the change is terrifying. Twice, as I realized how ill I was, I saw these changes coming and was overwhelmed by them.

—Arthur Frank, *At the Will of the Body*

When Margaret arrived at the door of the cancer center, there was a meeting of strangers. We know how it felt to be the receiving host, but how did it feel to be Margaret, the patient-stranger? We're not sure because our procedures did not, and do not now, include asking for the patient's thoughts and feelings about her illness experience. However, the memoirs of other persons who have lived with cancer are replete with thoughtful and heartfelt descriptions of the patient-stranger's experience. Surely they describe some of Margaret's experience as well. This chapter gives the reader an opportunity to practice being a witness, attentively listening to the testimony of those who have experienced cancer firsthand. (More testimony can be found in the endnotes.) In minimizing commentary, I, too, practice being present with the patient-stranger's suffering through attentive listening. In this chapter and the next I have included each person's name purposefully. They who have lived with cancer are not anonymous or invisible; naming them is one small way I can recognize each one's suffering and courage.



### Terrified

“As I sat in the waiting area with my wife, I was uneasy with apprehension. The horror stories I’d heard about chemo were terrifying. I was convinced my hair would fall out and then my teeth, and finally, I would succumb to massive weight loss and weakness throughout my entire body.” (Jerome Hill)<sup>1</sup>

### Knocked for a loop

“A year ago I was told I had an 80% chance of having breast cancer. That time, the biopsy was negative. . . . So this fall I met cancer, as it were, from a considered position, but it still knocked me for a hell of a loop, having to deal with the pain and the fear and the death I thought I had come to terms with once before.” (Audre Lorde)<sup>2</sup>

### Out of control

“When you learn that you have cancer, the world spins out of control. You are thrown into a world of medical procedures and inconclusive diagnoses. What’s more, you have to interact with technicians and medical professionals, many of whom can be insensitive. The texture of your social relationships changes. Your friends and family may shower you with too much attention and concern; they may talk too much about your disease. Some of your friends and family may seek comfort in denial; they avoid the subjects of illness and death. Meanwhile, you find yourself in the vortex of a whirlwind. No matter what kind of support you have from friends, family, and professionals . . . the cancer cells have appeared in your body, which means that ultimately you . . . must face your fate alone. (Paul Stoller)<sup>3</sup>

### In a nightmare-dream

“What was it like to be told I had cancer? The future disappeared. Loved ones became faces I would never see again. I felt I was walking through a nightmare that was unreal but utterly real. This could not be happening to me, but it was, and it would continue to happen. My body had become a kind of quicksand, and I was sinking into myself, my disease. (Arthur Frank)<sup>4</sup>

### Demeaned

“I felt like a piece of meat. Technicians touching my breast, measuring my breast with cold instruments, marking it with felt-tip pens, talking to the back of my head, not introducing themselves to me even though I asked them to. I was an object. I felt demeaned, violated by unwanted fingers touching my body.” (Lena Albert)<sup>5</sup>

### Mutilated

“After two and a half years, I still get anxious in the quiet hours of the night when I “remember” the surgery; a stranger tearing my body apart, ripping out my uterus and then discovering that lesion on my left ovary. And the pain. I can still *feel* the pain. I couldn’t believe they cut this beautiful body in half, sliced and diced it, my guts out on the table like a string of raw sausage.” (Janet Greene)<sup>6</sup>

### Flattened

“People speak of illness as deepening. I don’t feel deepened. I feel flattened. I’ve become opaque to myself.” (Susan Sontag)<sup>7</sup>

### Ashamed

“Then the nurse’s refusal to say the word “cancer” told me that what might be happening to my body was too awful to be called by its proper name. I was suddenly ashamed of what might be wrong with me. In the silencing of the word “cancer,” I as a person with cancer was also silenced.” (Arthur Frank)<sup>8</sup>

### Isolated

“Coming home from the hospital, it was hard not to feel like a pariah. There were people who avoided me out of their own pain or fear, and others who seemed to expect me to suddenly become someone other than who I have always been, myself, rather than saint or Buddha. Pain does not mellow you, nor does it ennoble, in my experience. It was hard not to feel pariah, or sometimes too vulnerable to exist. The status of untouchable is a very unreal and lonely one, although it does keep everyone at arm’s length, and protects as it insulates. But you can die of that specialness, of the cold, the isolation. (Audre Lorde)<sup>9</sup>

### Powerless

“In a flash, cancer had abruptly taken control of my life and forced me onto a dreadful new path that promised unspeakable pain and endless suffering. The terrifying prospect of a slow and unbearable death made me tremble. These frightening thoughts quickly transformed me into a powerless person. I wanted my old life back, but in my dazed and confused state, I felt incapable of recapturing it.” (Paul Stoller)<sup>10</sup>

### Not Special

“What is it that’s so depressing about this [mastectomy camisole] . . . Its genericness and ugliness. The lack of adjustable straps. It’s one-size-fits-all, Iron Curtain-like, Army issue-ness. The camisole is not like any camisole you would buy voluntarily. I guess it reminds me of the dailiness of the cutting and scooping and sewing that Fancy and every other hospital does day in and day out, one breast after the other, bring on the next one, hup hup. Praise the Lord and pass the ammunition. A mastectomy is a singular event in a woman’s life (one hopes), and it’s just ho-hum in the lives of the surgeons and nurses. As we lie on the gurney with tubes and monitors attached to us, we are not, as the rose said to the Little Price, unique au monde. We are dead to the world, all blood and tissue. We’re all just hamburger, says my friend Fred. And tumor. Don’t forget tumor. (S. L. Wisenberg)<sup>11</sup>

### Exhausted

“I mostly sleep with my head on the kitchen table.” (Margaret, when I asked where she slept and if she wanted me to get her a hospital bed to replace her mattress on the floor)

### On a journey

In the writings of people who have dealt with cancer are a multitude of references to the cancer experience as a journey; the caregivers are often described as companions on the journey.

“During the first hours, days, and months of the breast cancer journey, a woman’s emotional strength is challenged in ways never imagined. . . . When one encounters

shining stars along this arduous path—and there were a few—one remembers them dearly. . . . Encountering professionals who not only smile but truly want to help and listen, and are actually top-notch in their knowledge and follow-through, adds a few souls onto this path and makes it seem less barren.” (Marj Green)<sup>12</sup>

As described in this chapter, cancer delivers cruel blows to the personhood of its hosts. Added to this is the necessity of leaving the safety and familiarity of home for a foreign land. Persons with cancer undertake this journey with hopes for safe and hospitable travel through alien territory.

## Chapter 6 - Alien in a Foreign Land

Now it is cancer's turn to be the disease that doesn't knock before it enters, cancer that fills the role of an illness experienced as a ruthless, secret invasion . . .

Susan Sontag, *Illness as Metaphor*

When you are diagnosed with cancer . . . you enter a new world, which in mainstream American culture . . . is a dark, fearful domain of pain and suffering. It is a place where most people don't want to go. It is a place most people don't want to talk about.

—Paul Stoller, *In the Village of the Sick:*

*A Memoir of Cancer, Sorcery, and Healing*

“Cancerland” is a provocative term. It is not my term; it is what many of those who have taken the cancer journey call the foreign experience of having cancer and receiving cancer treatment. Although some writers have intended to communicate humor, sarcasm or bitterness when referring to “cancerland,” most people describing their experience as an alien in a foreign land do so earnestly, and cancer memoirs abound with images that convey the feeling of foreignness. The testimony is convincing and supports a view of the person with cancer as a stranger in need of hospitality. As in the previous chapter, these representations are sufficiently coherent without interpretation and afford the reader further practice in witnessing. Out of the multitude of testimonies, I have included only one for each heading; many more are located in the endnotes.

### Lost without a map

“Serious illness is a loss of the ‘destination and map’ that had previously guided the ill person’s life.” (Arthur Frank)<sup>1</sup>

### A new world - a foreign land

“It was October 17, 2000, and I was suddenly and unexpectedly terrified. Everything familiar was replaced by a world of white coats and needles . . . I remember that winter of 2000, when time seemed to stand still. I entered an alien world—the world of cancer.” (Paula Kruse)<sup>2</sup>

### A foreign language

“I don’t remember exactly what I said. Something about being in remission. I laughed, but she didn’t. . . .She said something about ‘traces.’ She said the scan last year, the same scan the doctor said ‘looked good,’ showed traces of cancer. I still had cancer. I was confused, too confused to ask questions. Too confused to wonder why the doctor hadn’t mentioned that I still had cancer during my last three office visits. Had it just never come up in conversation? The nurse said when the doctor told me the scan ‘looked good,’ he meant the cancer hadn’t spread, not that it was gone. I work in words. I know their power. The doctor had said it ‘looked good,’ the same as saying ‘You’re cured,’ right? In journalism we call it paraphrasing a quote. I paraphrased that quote for a full year to my family, my friends, myself, telling everyone I was cured.” (Christine Barber)<sup>3</sup>

### The foreignness of battle

“A person who is told she has cancer faces a hideous recognition that something monstrous is happening with her own body. . . . And then, suddenly, within the rooms of

secrecy, patient, doctor and family find themselves engaged in war. Once again, medical language is loaded, this time with military metaphors; the fight, the battle, enemy infiltration, and defense strategies. I wonder if this kind of aggression waged against our own bodies is counterproductive to healing? Can we be at war with ourselves and still find peace?" (Terry Tempest Williams)<sup>4</sup>

#### A stranger unto oneself

"I'm sick of hearing that cancer is transformational. I liked my life just fine before. It didn't need to be transformed. I was progressing on my journey *just fine!* And then whammo! Cancer! It doesn't feel so much like transformation as like being blown to pieces, to smithereens, with body fragments careening into the sky like deadly little missiles and plunging back into the earth like meteor shards. And now I get to put the pieces back together, but I swear they're not all part of the same puzzle. Instead I have a shred of cloud-filled sky next to a piece of running water above a twisted remnant of a dog's tail below a lizard's splintered eye. . . . Transformation, schmansformation! I just want my life back." (Patsy Sears)<sup>5</sup>

#### Alien invasion

"As TB was the disease of the sick self, cancer is the disease of the Other. Cancer proceeds by a science-fiction scenario: an invasion of "alien" or "mutant" cells, stronger than normal cells." (Susan Sontag)<sup>6</sup>

#### Colonization

"I, my body, became the passive object of this necessity, the investigation. I could imagine how native people felt when European explorers arrived on their shores, planted



a flag, and claimed their land on behalf of a foreign monarch who would bring civilization to the savages. To get medicine's help, I had to cede the territory of my body to the investigation of doctors who were as yet anonymous. I had to be colonized.” (Arthur Frank, responding to a doctor telling him, “This will have to be investigated.”)<sup>7</sup>

#### The liminal state of remission

“Cancer patients, of course, are not the only people who live in a continuous state of liminality. Consider the lives of immigrants. They leave their ancestral homes and settle in new lands in which the language is foreign and the customs are exotic. Even if immigrants have a long history in their adopted lands, they may not truly feel at home. Even if they return to the land of their birth, their experience overseas will have changed them. They will see home through different eyes; concomitantly, the people at home will also see them differently. These dynamics, which may make the immigrant feel out of sorts, sets a course of continuous liminality.” (Paul Stoller on the experience of living in between the village of the healthy and the village of the sick.)<sup>8</sup>

#### Invalid in the world of sickness

How did you pronounce the first word in the line above? *In*-valid? Or *in*-*valid*? Although Irving Zola was not writing from the perspective of a person with cancer, his comments on the prejudices toward those living in the world of the sick are pertinent to the cancer experience. “The very vocabulary we use to describe ourselves is borrowed from [the normal world]. We are de-formed, dis-eased, dis-abled, dis-ordered, ab-normal and, most telling of all, called an in-valid. And almost all share deep within ourselves the

hope for a miracle to reverse the process, a new drug or operation which will return us to a life of validity.”<sup>9</sup>

For Jon with growing metastatic cancer, being an invalid—which he perceives as being *in-valid*—is worse than not-being. “When you’re on the computer and you do something wrong or bad, it comes up ‘invalid.’ I don’t want to be that!” he literally cried to me. He talked at length about his sadness at having to leave his job because he knew he couldn’t handle the heavy responsibilities. He was proud of his important work and technical expertise; he had been promoted to a position in which he was the go-to man—“Ask Jon, he’ll know.” Not yet 40, he is determined to avoid the foreign world of disability and invalidity at all costs. He has thought of taking his own life, and hasn’t ruled out the possibility. How can I help him remain in the familiar world of validity? His pain is a pressing issue that requires immediate attention; his need for counseling a close second. Finding venues for the restoration of his sense of validity will take time Jon doesn’t have. He’s building computers for his family for Christmas. Chances are he will die before their gifts are unwrapped.

When we listen to the voices of persons living with cancer, we know without a doubt the value of practicing deep hospitality toward these strangers reluctantly knocking at the door of the foreign land of cancer.

## Chapter 7 - Door

I heard my name called. Again they called me Lucinda. Previously that name had belonged only to the first day of school, but from that moment on I recognized it as the property of all people in uniforms standing in the unflattering fluorescent light of hospitals. —Lucy Grealy, *Autobiography of a Face*

The day our cancer center opened for the first time, there was no welcome sign. There were a linear accelerator and a beautiful new building, worth 12 million dollars. There were highly-trained staff worth hundreds of thousands of dollars. But there was no welcome sign, which, I thought at the time, may have been priceless to the stranger knocking at that door.

While there was no welcome sign, there *was* a great deal of excitement about having radiation oncology close to home, after more than twenty years of wishing and a decade or so of concentrated effort. By the looks on the faces of the VIPs attending the Open House (there was no public open house because, I was told, we couldn't risk anyone touching the expensive equipment), nobody else was bothered by the absence of a welcome sign. If they had been, they would also have been disturbed by the signs leading into the hospital's main entrance, just a few steps from the cancer center: *Smoking is not permitted; Guns and Weapons are Prohibited; Caution—Automatic Door; Caution—Stand Back; These doors are locked at 9:00 p.m.; This area is monitored by surveillance cameras; Don't share—keep germs from spreading.*

When my 7 and 9-year-old grandchildren and I drove from Vermont to see their great-grandfather in New York, we read all the welcome signs. “Head’s up! Someone read this one,” I’d holler. “Welcome to Connecticut!” they cheered. It made entering the foreign states of Massachusetts, Connecticut and New York cause for celebration. An open door in healthcare is a necessity and by itself does not give cause for celebration. One reason we open the door to the patient-stranger is to stay in business. We’d have a hard time paying our bills and retaining our staff if we kept our doors closed. A second is that we are *mandated* to open our doors to serve the public. Regulations prohibit opening the door to only friends and keeping it closed to strangers. An open door alone doesn’t communicate welcome to the patient-stranger. We must also be intentional in adopting welcoming practices.

#### Warmth and benevolence—a glance, a smile, a greeting

Whoosh . . .

That’s the sound of doctors, nurses, technicians and social workers breezing through waiting rooms. I sometimes think we should have those comic book word clouds accompany us as we rush past the biding patients and their families on our way to somewhere more important. Whoosh! Zip! Whirr! To those of us on the run, our focus is admirable; we have important tasks to tend to in the service of healing. Perhaps, though, the ones passed by see us more like a Batman and Robin fight: Bam! Pow! Slap! While a patient sits trying to keep her anxieties at bay—awaiting the humiliation of stripping, anticipating bad news, dreading the discomfort of treatment—we scurry by in our good health, clutching our ever-so-vital documents and deeply engaged in our multi-thinking:

Where is my next meeting, which calls do I still need to return, what should I fix for supper tonight?

Several years ago I participated in an e-course called *Practicing Spirituality at Work*. Each day I received an e-mail containing a quotation, commentary and practice. One morning's e-mail contained the quote: *Greet your coworkers. Greet your coworkers? How ridiculous! And what does that have to do with spirituality? The quotation was from Gabrielle Roth. "A taxi driver once told me that no one in his African country gets on a bus without greeting every single person on it. It's unthinkable not to do so, not to honor a sense of something larger than a solitary self."*<sup>1</sup> I have never let go of that straightforward advice. It is on my mind every workday, especially when I am harried and really don't feel like greeting anyone. On those days I'm reminded of another message from the e-course—*Be aware of how you affect others*—with an accompanying quote by Eknath Easwaran: "In my teaching days in India, when I would remind a student that he was looking a little gloomy, he would object, 'But sire, its' my face.' I would reply, 'Yes, but it's we who have to look at it.' Not even the look on our face is our own business; all these things affect the people around us."<sup>2</sup>

We might not know what anxieties or sorrows a person is carrying when she arrives at the door of cancerland. It could be as significant as a fear of dying and as small as distress from the challenges of parking the car. Shortly after beginning my new work, I had to drive to Fletcher Allen in big-city Burlington. I had some mild anxiety, not quite sure how to get there or where to park. Following the signs, I came to a dead-end, turned around and finally landed at the monstrous parking garage. Then into the building with

butterflies in my belly, still concerned about how to get to my destination. All of my worries were put to rest by the kind reception I received at the main desk. Chances are the volunteer knew from experience what a treasure a warm greeting is to an anxious stranger. Imagine the impact of the greeting on the patient-stranger shouldering the weight of the world as he arrives for cancer treatment!

Paul Stoller's chronicle of his experience receiving cancer care was where I first found a reference to "warmth." The nurse smiled warmly; the doctor "greeted us warmly and shook our hands."<sup>3</sup> This is in contrast to another experience he had at the same medical center, in which "everyone . . . seemed sullen . . . the nurse frowned," spoke blandly and shrugged.<sup>4</sup> He's an anthropologist, I thought; noticing small things and finding big meaning in them is what he does. But time and again I came upon references to warmth by survivors of cancer who haven't had ethnographic training. Patients who nominated their oncology nurses for an award sponsored by CURE magazine identified warmth as a winning attribute. "Initially, I was numb. Then that cold feeling gave way to fear of surgery, chemotherapy, radiation, and death. And that was exactly what I faced as I presented myself at the oncologist's office on a cold Friday morning in January for my first chemo treatment. Cheryl greeted my husband and me with a warm smile."<sup>5</sup> Warmth is frequently associated with smiling. In another CURE nomination Jerome Hill describes how a smile can banish fear. "As I sat in the waiting area with my wife, I was uneasy with apprehension. The horror stories I'd heard about chemo were terrifying . . . Then my nurse walked in: Marilyn Thompson was unlike any health care professional I'd ever met.

As cliché as it sounds, her brightness and smile gave off an aura of sunshine. I was immediately comforted.”<sup>6</sup>

In a story about visiting with her dying godfather, Rachel Naomi Remen affirms the value others have ascribed to being received warmly. “He smiled at me, a beautiful smile, and said, ‘I’ve been waiting for you.’ . . . My godfather’s eyes and his smile were full of a great love and appreciation. For the first time I felt a deep sense of being welcome, of mattering to someone.”<sup>7</sup>

While Remen records her godfather’s words, it’s what he communicates through his smile and his eyes that affects her so deeply. In cancer care, we can’t always greet people with words. Sometimes time is the culprit and we really do need to whoosh by; at other times the circumstances just don’t allow for conversation. In such situations, we can practice “benevolent glancing.” Roman Catholic sister Mary Evelyn Jegen describes benevolent glancing as using one’s eyes for “appreciative receiving rather than taking.”<sup>8</sup> This concept is especially apt for our practice of hospitality, which concerns itself with how we *receive* the stranger. It is in the *space* stage of hospitality practice that our receiving fully blossoms, but we can begin it the moment we open the door. When Jegen read about the “fraternal glancing” between the Pope and a Buddhist patriarch, she wondered what it would feel like to look at a stranger benevolently. In practicing benevolent glancing on a public bus in Chicago, she found herself praying for the person, not with prayers but with attentiveness; she discovered that using only her eyes she was able to *wish another person well*, which is the meaning of the word *benevolence*. This is reminiscent of Miroslav Volf’s “hermeneutics of charity,” in which we are able to

interpret the other with the eyes of love. With a gaze of love, we excuse what is problematic and highlight what is beautiful.<sup>9</sup>

Jegen's discussion of benevolent glancing is found in her writings about choosing active non-violence over violence. She uses the metaphor of healing wounds to describe active non-violence, asserting that healing occurs when one can be fully attentive to the other. Looking upon another with benevolence—wishing that person *well*—extends the healing metaphor, making it particularly appropriate for the health care setting. Jegen believes that looking upon another with benevolence “requires an inner stillness and peace,” a personal state I've haven't quite perfected.<sup>10</sup> Nevertheless, since entering the world of cancer care, I've been working on my glance. Arriving at the Cancer Center from my office in the hospital, I open the door with a conscious awareness: who will be in the waiting room and how will I greet them? These patients and families don't know me like they know the radiation oncology staff with whom they interact every day. Some of them don't expect me to address them heartily, and I feel that sometimes a word, a nod, a glance and a smile is a respectful way to receive these patient-strangers. Through eye contact I try to communicate my gladness to see them and my wishes for their well-being.

### I recognize you

One step beyond acknowledging a person's presence with a greeting is communicating recognition. It's possible to communicate *I know you* to even a stranger. Recognition is especially important to those who've entered the foreign land of illness. Irving Zola noted this in describing his experience in an intentional community for



handicapped persons in the Netherlands. “Wheeling up to the desk I spied the familiar face of someone I saw on my first visit in January. She was the receptionist, and her smile of recognition comforted me.”<sup>11</sup> Calling a person by name is an act of recognition, but only if we get the name right. Are we pronouncing it correctly? Are we using the name he or she prefers? Getting the name wrong communicates a lack of concern about the person as an individual. In the quote that opens this chapter, Lucy Grealy recalls the effect of being called Lucinda by medical personnel.<sup>12</sup> Worse yet is the fairly common act of referring to people by their disease rather than name—usually not in their presence, but such a practice results in caregivers putting distance between themselves and the human person. Arthur Frank recalls an incident in which a nurse speaking to his wife referred to Frank as “‘the seminoma in 53’. . . . The hospital had created its own version of my identity. I became the disease, the passive object of investigation and later of treatment.”<sup>13</sup>

When Oliver Sacks arrived at the hospital after having a skiing accident that resulted in paralysis, he was terrified. “And I was seized, overwhelmed, by this dread, this elemental sense and dread of degradation, throughout the dragged-out formalities of admission, until—suddenly, wonderfully—humanity broke in, in the first lovely moment I was addressed as myself, and not merely as an ‘admission’ or *thing*.”<sup>14</sup> He was referring to an incident in which his nurse unpacked his bag and found no clothing, only books. “Oh, Dr. Sacks!” she laughed heartily, causing him to laugh in return. The simple act of being called by name contained the power to banish his trepidation.

It is Sacks who points out how depersonalizing medical admission procedures can be. In addition to having one's own clothing replaced by the facility garment and being required to wear an ID band, the patient is expected to abide by the rules. "One is no longer a free agent; one no longer has rights; one is no longer in the world-at-large . . . One is no longer a person—one is now an inmate."<sup>15</sup> Many improvements have been made in the twenty-five years since Sacks made that observation. Nevertheless, the cancer center would do its patient-strangers a service by examining its procedures with an eye for affirming the patient-stranger's unique personhood. Frank notes a more subtle form of impersonal treatment. "To be ill is to be dependent on medical staff, family, and friends. Since all these people value cheerfulness, the ill must summon up their energies to be cheerful. Denial may not be what they want or need, but it is what they perceive those around them wanting or needing."<sup>16</sup> There is understandable variation in individuals' responses to the diagnosis and treatment of cancer. Yet in my experience, Frank is correct: we feel more positively toward patients who are cheerful and humorous than to those who are sad or angry. In the practice of hospitality toward the patient-stranger, we would allow each person to respond to his and her unique circumstances in an organic way, rather than imposing the responses we prefer.

#### Acts of kindness

It is remarkable what a difference small acts of kindness are to persons bearing large sorrows. The encounter between my grieving father and the hotel clerk is a personal example. Lucy Grealey's story of her last day of years of grueling cancer treatments, when she was a young girl, is equally poignant. She describes her final encounter with a

hospital housekeeper who had quietly offered her a cup of tea at the end of each previous treatment, which Lucy had always declined.

“How do you feel?” [Hannah] asked. I began to cry. Just a little bit at first, but soon I was sobbing and my whole body was shaking. I tried to stop, but it was out of control, and I gave myself over to it. Hannah bent over and put an arm on my shoulder for a second, only for a second, then withdrew it and straightened up. She stood there for a few moments holding her hands together over her stomach, then, without asking, busied herself making me the cup of tea she’d been offering me for years . . . Slowly the crying began to stop. I felt so tired all of a sudden, but quietly tired, in a restful way, not the usual exhaustion.<sup>17</sup>

Remen points out that we are often unaware of the meanings such simple acts of kindness hold for the recipients. She also suggests that people can meet each other in these small moments. A benevolent glance, a warm smile, a sign of recognition, a small act of kindness. These are all welcoming practices that belong to the *door* stage of the deep hospitality we can extend to the patient-stranger entering cancerland.

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Deep hospitality practices in the *door* stage:

Communicate welcome and greet warmly

Call the patient by the right name

Practice benevolent glancing

Personalize facility procedures

Invite individual responses

Perform small acts of kindness

## Chapter 8 - Table

[The anesthesiologist] refused to look at me, and he even had the facts of the planned operation wrong. When he was leaving I did the worst thing to him I could think of: I made him shake hands. A hand held out to be shaken cannot be refused without direct insult, but to shake a hand is to acknowledge the other as an equal. —Arthur Frank, *At the Will of the Body*

A favorite hymn at our church is “Won’t You Let Me Be Your Servant?” The title belies the hymn’s real theme, contained in the first two lines: *Won’t you let me be your servant, let me be as Christ to you? Pray that I may have the grace to let you be my servant, too.* To invite the stranger to your table is to blur the line between servant-host and guest. It is to acknowledge, regardless of the immediate circumstances, our common humanity: we are all works of art; we all have our experiences of joy and sorrow, triumph and disappointment; we all need others. The hymn continues, “*We are pilgrims on a journey, we are travelers on the road. We are here to help each other walk the mile and bear the load.*”

Patients are not the only ones on the cancer journey; their families, friends and professional caregivers travel with them. It is both a benefit and a hazard that helpers like doctors, nurses and social workers want to be the *givers* in their relationship with patients. The hazard is that, as a result of the professional’s expertise and the patient-stranger’s vulnerable condition, it would be easy to establish a superior-subordinate relationship. Being helpful makes my day and literally puts a spring in my step. It also boosts my ego, which can have the unintended consequence of communicating too much

confidence and too little vulnerability. A study of clinicians identified as exemplar healers demonstrated that while patients value their practitioners' self-confidence, they also appreciate humility. "Clinicians are seen as more knowledgeable if patients perceive that they know their own limitations and display a willingness to seek assistance when those limits are reached. 'To admit when you don't know something—you're human. Wow!'"<sup>1</sup> Writing about the first time he met his oncologist, Paul Stoller noted a winning combination of traits. "I liked the contradictions that he presented. According to Brian Markson, he was a straight shooter, a feature that corresponded to his strong features. At the same time, he seemed like a person willing to express his vulnerability."<sup>2</sup> When the caregiver communicates the right balance of confidence and vulnerability, the patient trusts the caregiver's competence and connects with his humanity.

In the *table* stage of deep hospitality practice, the practitioner and the patient meet as equals and the roles of host and guest are fluid and non-hierarchical. This takes awareness and effort to achieve because it is contrary to the traditional relationship. Marianne Paget's eloquent description is an example of this tradition:

She and he confronted each other across the chasm of his technical knowledge and his technical practice of questioning her. She was on the other side with her fear of her death. He could not feel; she could not stop feeling. He could not listen to her fear; she could not stop expressing her fear which he couldn't or wouldn't hear. He was the-one-who-would-not-listen and she the-other-who-was-not-heard, archetypes of an experience each of us knows.<sup>3</sup>

Susan Sontag, who wrote about cancer in her bold classic *Illness as Metaphor*, was less intrepid in her own experience being treated for a blood cancer called myelodysplastic syndrome. Her son, David Rieff, commented on his assertive and independent-minded mother's deference to her physicians, referring to "that profound (and probably inevitable) infantilizing asymmetry at the heart of what goes on between doctors and patients."<sup>4</sup>

There is an asymmetry in the patient-caregiver relationship that we are tempted to consider natural, but human nature tells us otherwise. Remen, Frank and Kleinman write extensively about the reality that we are equal in our vulnerability because we all live with suffering, uncertainty and woundedness. When we deny that vulnerability, we silence our patients, diminish their trust in us, distance ourselves from them, inhibit our compassion, and deprive ourselves of knowledge we need to cope.

#### Mutual vulnerability

When Irving Zola took to a wheelchair to get a feel for the experience of the physically disabled residents of the Het Dorp community, he found himself in an uncomfortable position of dependency. He did not like the feeling of obligation that came with asking for favors. He was concerned that people would see him as weak. And he suspected this would be especially true in the United States, where the citizenry live by the truism, "It is far better to give than to receive."<sup>5</sup> Arthur Frank had a similar experience during his cancer treatment. "Admitting that you have problems makes you vulnerable, but it is the only way to get help. Throughout my illness Cathie and I constantly weighed our need for help against the risk involved in making ourselves

vulnerable.”<sup>6</sup> Equal amounts of vulnerability and support were acceptable, but minimal support from caregivers was not worth the risk of making himself vulnerable. John Updike, remembering his battle from an early age with disfiguring psoriasis, noted, “Children are frank, as we know from the taunts and nicknames they fling at one another; but also they all feel imperfect and vulnerable, which works for mutual forbearance.”<sup>7</sup> These are just a few of many first-person accounts of how unsafe it feels to be vulnerable and how important it is to be in the company of others willing to demonstrate vulnerability. If the practice of hospitality calls for relationships of equality as far as possible, and if vulnerability is an unavoidable companion to illness, and to cancer in particular, it becomes the practitioner’s responsibility to identify and communicate vulnerability.

Remen provides a persuasive example of this in one of her stories. She was seated on a flight next to a man who dropped his yogurt onto his foot and because of physical impairment was unable to clean it up himself. He was embarrassed by the incident and the flight attendant’s unsympathetic reaction. Remen, noting his physical disability, shared that flying has been difficult for her because she has trouble seeing. In turn, he told her that he’d had a stroke and in addition to having some paralysis he was also incontinent. She responded that she had an ileostomy and worries about it leaking, especially when she flies. She then asked for his permission to wipe the yogurt off his shoe and, consenting, he leaned forward and said to her, “I used to play the violin . . .”<sup>8</sup>

A co-worker told me about her mother who died of cancer. I asked how her mother had liked her oncologist, expecting her to praise him, since most patients and

families do. She answered that her mother liked him just fine while she was getting active treatment but felt abandoned by him when medicine couldn't help her anymore. Others have told me that this doctor takes it hard when he can't keep his patients alive. "There's nothing more I can do," is a blow to a patient; it's also a falsehood. Doctors and other caregivers can embrace their own vulnerability and summon the courage to be present with the patient in her suffering; at the very least, that presence will communicate caring rather than abandonment.

Frank Ostaseski, co-founder of the first Zen hospice in the U.S., names "bring your whole self to the experience" as one of the precepts of care for seriously ill persons. "Bring your whole self . . . not just your expertise. [Bring your] fear, confusion, woundedness, helplessness; we can't travel with others in territory we haven't explored."<sup>9</sup>

For a practitioner who is used to leading with competence and confidence, getting in touch with a sense of vulnerability in a natural and sincere way requires practice. It is worth the effort, because it provides an opening to suffering patient-strangers to connect on a human level and make their needs known.

#### An egalitarian environment

As Frank noted, a handshake is a symbol of equality, and it is a painless practice to adopt. It is also easy for us to create an environment that supports egalitarianism. Do desks separate us from the patient-stranger, emphasizing difference and distance? Do we afford the patient the same privacy we reserve for ourselves? Do any of our procedures depersonalize our patients?



One national healthcare safety goal is to assure that care is being given to the correct person. To meet that goal, our cancer center keeps a picture of each patient in the electronic record. I was dismayed to see that the pictures are usually taken after the person has changed from her own clothing into a generic hospital gown. Is there any garment that surpasses the “johnny” in transforming a self-confident, capable, independent person into an inadequate, helpless sap?<sup>10</sup> For care providers to view such pictures every day subtly reinforces the imbalance in the relationship. The providers in their crisp scrubs or neat office wear, the patients in thin, ugly, shapeless, backside-exposing gowns. Margaret insisted that her picture be retaken. “I look like a frog,” she said, and she was right that it was a horrible photo. Despite all the major issues she was dealing with, some of them life-and-death, a dignified picture was a priority. Margaret overcame some of the imbalance in the patient-provider relationship through the act of asserting herself and the accomplishment of having a new picture that was a more desirable image.

### Get personal

Patients do prize technical skill, and I’ve heard people say that if they had to choose between competence and bedside manner, they’d pick the former. It’s unfortunate that this “what if?” question ever has to be asked. People who have life-threatening illnesses—especially those whose illnesses will never be cured—appreciate having caregivers show a personal interest. Arthur Frank provides a clear example from his own experience. “Even though my worst fears were realized in what he said, the physician showed, just by the way he looked at me and a couple of phrases he used, that he shared

in the seriousness of my situation. The vitality of his support was as personal as it was professional. Physicians I encountered later were optimistic about my diagnosis and prognosis; he was almost alone in expressing optimism about me, not as a case but as a person.<sup>11</sup>

It was at my third tumor conference that I realized how easy it would be to focus on the cancer and forget the person. Medical centers that treat cancer have regular multidisciplinary meetings to discuss their patients' cancers. These "tumor conferences," are attended by oncologists, surgeons, radiologists, pathologists, other specialists, the cancer registrar, and ancillary staff like nurses and social workers. My sense of being a stranger in a strange land was reinforced when I attended my first tumor conference. The patients' scans and tissue specimens were in enlarged view for all to gape at; I had no idea what I was seeing and no translator for the exotic language. By the third conference, I recognized how fascinating this was for the clinicians, and I understood how someone might be captivated by the science and leave the person behind. I am happy to report that for the most part this is not the case. It's true that the pathologists, who never meet the patient, focus entirely on the cancer. And the radiologists, who meet the patient only briefly, rarely have anything to say about the person. But the good news is that those clinicians who have personal contact with the patients do not leave that experience at the door. The surgeon or oncologist comments on the patient's wishes and expresses sympathy when the person's symptoms are distressing. *She's ready to go to Florida with her husband for the winter so we have to figure out how to make that happen for her. / This unfortunate gentleman has his daughter's wedding coming up; let's do what we can*

*so he can walk her down the aisle. / She's frail and tired and thinks it's all been too much; we'll find a more conservative approach.*

Frank elaborates on the value of getting personal. He recalls one time a physician abruptly told him he had massive tumors. “He would send a report to my family physician; that was it, not even a goodbye or good luck, just over and out. It was a triumph of science and a lapse of humanity.”<sup>12</sup> It is gratifying to know that our tumor conferences address science and humanity in equal parts and that each person’s individual preferences are honored.

### Stories that connect

With patient-strangers who are very different from ourselves, finding points of connection can be difficult. All too often I succumb to the temptation to share with coworkers stories that highlight the extreme behaviors and personalities of some patients, even, I’m ashamed to admit, stories about Margaret. Then we sigh, laugh or roll our eyes. I am grateful to Inui and Frankel for their humanistic insights about this common, longstanding practice.

The more the stories we construct or exemplify in our work are about the *differences* between self and other, the more likely it is that understanding will be tempered, and perhaps distorted, by stereotypical thinking, suppression of true self, defensive posturing, personal isolation, and play-acting rather than the bringing of our whole self to work. Finding a “common story” that joins self and other in each situation is not always easy or possible. Deeper understanding of ourselves as well as of others is apt to be required to succeed in challenging

circumstances. More times than not, however, expanding our perspective to ask about each situation—“In this story, where am I? Where is the other? Where is the common good? What, then, should I do?”—will produce a different appreciation of the situation; one in which more of the whole is possible to discern and from which Samaritan medicine emerges.<sup>13</sup>

Our commitment to meeting the patient as an equal requires that we highlight our similarities with patients and understate our differences. This work begins with an invitation to the table and continues when we practice making space in our hearts and minds for the patient’s ideas and ways, strange as they may seem. By adopting the deep hospitality practices covered in this chapter, caregivers can transform their centers into *kitchen* tables, where, as Remen asserts, “everyone’s story matters.”<sup>14</sup> The mutual learning that will lead to healing happens in the final stage of the practice of deep hospitality—*space*.

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Deep hospitality practices in the *table* stage:

Shake hands

Have patient wear own clothing when possible

Sit away from desks

Have food or beverage together

Tap into your own vulnerability; communicate vulnerability to patient

Get personal

Tell connecting stories to other practitioners

## Chapter 9 - Space

Perhaps the most basic skill of the physician is the ability to have comfort with uncertainty, to recognize with humility the uncertainty inherent in all situations, to be open to the ever-present possibility of the surprising, the mysterious, and even the holy, and to meet people there.

—Rachel Naomi Remen, *My Grandfather's Blessings:*

*Stories of Strength, Refuge and Belonging*

Gary was hard to read. He talked minimally, didn't smile, kept his distance. He asked to see me and it was only a cut-and-dry insurance question. He gave no opening for me to charm him with my desire to learn about his concerns. The radiation therapists said, "He's a strange one." They, too, depend on charm to win patients over but Gary was immune to it. His wife told me that Gary kept his cancer secret from her and their children for several weeks. One day, when she was at the hospital for a non-medical purpose, she and her daughter bumped into Gary. "What are you doing here?" they inquired and he mumbled a fabricated answer. Not long afterward he revealed to them that he'd been diagnosed with throat cancer and had arranged for chemotherapy and radiation treatments. His wife worked hard to understand why he had kept such a secret and to reconcile that act with the Gary she knew. She made space in herself for this Gary she didn't know. And she literally gave him space, allowing him to camp out in the

basement (he didn't want anyone to be bothered by his nausea and general malaise) and to stay away from family meals (at an early point in his treatment he couldn't swallow and received all his nourishment from a feeding tube). With his family practicing this element of hospitality—accepting the Gary who was a stranger to them—Gary healed, survived, and thrived.

I encountered Gary several weeks later, when he was leaving the center after a follow-up appointment. For just a moment I wondered, *Who is this man?* He looked fabulous, wearing a nice dress shirt and a broad smile. I couldn't resist giving him a congratulatory hug and he returned the embrace. A couple of months later, our secretary sent this e-mail to the team: *Gary just stopped in. He asked me to be sure to tell everyone how much he appreciates all of us and this facility. He says that to have this place here and people like us is a lot to be thankful for. He is doing very well and expressed gratitude toward all of us!*

This chapter expands on the discussion of the *space* element of deep hospitality practice in chapters 2 and 4 by adding the thoughts and feelings of persons living with cancer to the foundation of Nouwen's insights on making space for the stranger. To review briefly, making space for strangers means to invite them to reveal and be their true selves. Emptying one's mind and heart of firmly-held beliefs and emotions puts the host in a receptive mode, resulting in the host becoming a guest in the stranger's life. Receiving the stranger's strangeness with openness and without judgment increases understanding and advances knowledge and growth.

I turn first to Carl Rogers, whose counseling concept of unconditional positive regard helps us identify the compassionate attitude the cancer care provider brings to the encounter with the person with cancer. Rachel Naomi Remen describes an experience at a gathering where Rogers was demonstrating the concept.

“Before every session I take a moment to remember my humanity,” he told us.

“There is no experience that this man has that I cannot share with him, no fear that I cannot understand, no suffering that I cannot care about, because I too am human. No matter how deep his wound, he does not need to be ashamed in front of me. I too am vulnerable. And because of this, *I am enough*. Whatever his story, he no longer needs to be alone with it. This is what will allow his healing to begin.<sup>1</sup>

In cancer support groups, encouragement comes from sharing with others who have had experiences similar to your own. Can the same kind of support come from persons like me, who have no personal experience with cancer? Rogers assures us that we can connect with others based solely on our humanity, if we approach the encounter with awareness of our own vulnerability and humanity.

Key components of the *space* stage of deep hospitality practice are presence and listening, which go hand-in-hand. It is a rare cancer-related publication that does not lift up the value of listening. Persons who nominated their oncology nurses for an award lauded them for being good listeners. “There is peacefulness about Tena’s listening. She listens with her complete self. Her eyes sparkle. She is attentive. She hears what I say and what I don’t say . . . She never speaks with her hand on the doorknob or ever says, ‘You

don't have any other questions, do you?"<sup>2</sup> Remen is the ultimate cheerleader for listening as a healing art and asserts that just silently listening to someone from the heart is sometimes all that is needed.

When we listen attentively, especially when we do so without interrupting to comment, the person can hear her own truth. Dean Ornish believes that part of the healing power of listening is that "we all have within us access to a greater wisdom, and we may not even know that until we speak out loud."<sup>3</sup> When we listen to a suffering person, we remind her of her value as a human being. And when we invite the patient-stranger to tell his story we provide an opportunity for the person to regain control of past and current events by telling the story however he chooses. Maura Spiegel and Rita Charon call this listening's "most radical power."<sup>4</sup>

Eliciting stories and attentively listening can also help meet the need for persons with cancer to achieve clarity that brings them a measure of freedom and comfort. "Clear" is an unexpected word located in several cancer memoirs. Paul Stoller states, "Cancer compelled me to see myself—my being—more clearly," adding that focusing on seeing things clearly comforted him in the uncomfortable state of having cancer.<sup>5</sup> Arthur Frank refers to his illness experience as walking on the edge, which "is not just an experience of fear; it is also a clarification. I have hiked trails high in the Rocky Mountains, climbing through thick fog. At a certain altitude the fog clears, and suddenly I can see all that lies below me. It may be a long drop to the bottom, but the view is spectacular, and it is only at the moment of clearing that I know where I am."<sup>6</sup> Remen tells a story of a therapist who gave her a bracelet with the word "clear" engraved on it.



“Sometimes it takes a lifetime to become clear. No matter. It may be the most worthwhile way to spend the time.”<sup>7</sup>

Listening isn't always easy. It requires us to be fully present, which is a challenge in this multi-tasking era. It involves silence, which is not natural for many of us. It makes us vulnerable to the reality of human suffering. Despite the opportunity for clarification afforded by storytelling, “listening to stories of illness and recognizing that there are often no clear answers to patients’ narrative questions demand the courage and generosity to tolerate and to bear witness to unfair losses and random tragedies.”<sup>8</sup> The hardest part of the kind of listening that is essential in the *space* stage of hospitality is emptying ourselves to make room for what the speaker is sharing. Again I consult Rogers, whose wise words on this subject echo those of Henri Nouwen. “For the time being, you lay aside your own views and values in order to enter another’s world without prejudice. In some sense it means that you lay aside your self; this can only be done by persons who are secure enough in themselves that they know they will not get lost in what may turn out to be the strange or bizarre world of the other.”<sup>9</sup> I suggest that in the practice of deep hospitality, we lay aside our own selves not to enter *another’s* world but to allow the stranger to enter *our* world. We receive rather than impose or impart. This is not to deny the importance of imparting skill and knowledge in cancer care. But healing the whole person also requires a receptive mode through which we take in his or her story. Gary’s healing happened through a combination of the skill of the cancer center team and the hospitable treatment from his family, who were able to make space in themselves for his strangeness, receiving Gary rather than imposing their desires and preferences on him.

Before we can listen, we need to create conditions that encourage the person to speak. There are many ways we unintentionally silence the patient-strangers who come to us for healing. Audre Lorde commented on the effect of the vapid hospital environment. “I found . . . that the very bland whiteness of the hospital which I railed against and hated so, was also a kind of protection, a welcome insulation within which I could continue to non-feel.”<sup>10</sup> Arthur Frank makes the same observation. “In the blandness of the medical setting, in its routines and their discipline, you may forget your tastes and preferences. Life turns to beige.”<sup>11</sup> Our cancer center is nicely decorated in . . . calming beige. I can’t imagine that the decorators considered that such a temperate scheme might discourage a patient from feeling and expressing feelings and desires. Who would know? But recently, when I was asked to meet with people in the patient support office rather than in a higher-traffic area, I pointed out that since the office was still unadorned it was not an appropriate meeting room. I think of counselors’ offices with green plants, warm fabrics, beautiful paintings and comfortable eclectic furniture and realize the universality of Lorde’s and Frank’s experiences.

We silence vulnerable persons with our personal discomfort talking about their illness. Paul Stoller’s excellent example of this involves his car ride with his brother for his first cancer treatment.

We drove to The Cancer Center in silence, avoiding the subjects of illness and life and death—something I had been thinking about for a month. . . . Instead we made small talk, mostly about the best way to get from my apartment to The Cancer Center . . . How strange it was that on such a traumatic day two men, for

whom talk is so important, would have such an impoverished conversation.

Halfway to The Cancer Center I finally said it. “I’m scared.”<sup>12</sup>

One of my first tasks upon taking the cancer care position was to become comfortable saying the word “cancer” to those who have cancer. I know that the days when cancer was considered an unspeakable word are long gone, but such fear and stigma die hard. Like Stoller’s brother and many other people, I was initially uncertain how to broach the subject. Not talking about it contributes to the person’s sense of isolation and shame. Talking openly and feely about it brings the person and her cancer into the light, making the experience more manageable and bearable, even more normal.

On occasion, we silence the patient-stranger through our negative responses to their differences. Inui and Frankel comment on this in their writing about healing narratives.

The people with whom we interact daily are often strangers, very different from ourselves. . . . And here is a different observation, not so much about them as about us—at times, they invoke responses within us that we don’t trust, admire, or find helpful, responses such as anger, disgust, horror, lust, or sheer boredom. Under these circumstances, we recognize the presence of another stranger in the clinical encounter—the *stranger within* each of us who has these reactions and must, at times, be suppressed because it gets in the way of successful service. At other times, this same “inner stranger” . . . needs to be brought more explicitly to our consciousness in order that we may mindfully pursue equity (instead of discrimination) in care decisions, understand and manage countertransference

phenomena, deepen our capacity for empathy, or acquire greater competency for working across cultures, ages, and/or genders. Humane medicine, humanistic medicine, patient-centered medicine, relationship-centered medicine—all may be founded on understanding what it takes to respond constructively and wholeheartedly to strangers, both to patients and to our innermost selves.<sup>13</sup>

Inui and Frankel are generous in calling the part of us that responds negatively a “stranger.” I find that all too often my colleagues and I are not mindful about our responses; regretfully, our negative side is more familiar than strange. Bringing that “inner stranger” to our consciousness in our encounters with patient-strangers could become one of our deep hospitality practices.

Arthur Frank has a great deal to say about the experience of feeling silenced during the treatment of his life-threatening illnesses. “Talking to doctors always makes me conscious of what I am not supposed to say. . . . I know I am supposed to ask only about the disease, but what I feel is the illness. The questions I want to ask about my life are not allowed.”<sup>14</sup> “The more extreme the situation, the more time and help I need to say anything. When I face someone who does not seem willing or able to help me work toward what I might eventually say, I become mute.”<sup>15</sup>

We can do better than this. But making space for the patient to say whatever he or she needs to say and making space in ourselves to receive that without judgment requires our commitment to awareness and practice. The medical literature abounds with studies about the importance of inviting patients’ narratives and the corresponding importance of practitioners developing narrative competence, defined by Charon as “the ability to listen

to the narratives of the patient, grasp and honor their meanings, and be moved to act on the patient's behalf."<sup>16</sup> Kleinman proposes that caregivers conduct a "mini-ethnography" for the purpose of understanding "the illness experience as the patient understands, perceives, and feels it."<sup>17</sup> Part of narrative competence is interpreting and responding to what the person shares. Remen is correct that there are times that listening with our full attention is all that the situation calls for. Other stories call for a response. In the practice of deep hospitality, we respond according to the patient-stranger's needs rather than our own, just as we attempt to see the person as she or he wants to be seen, putting aside our preferences and prejudices. Lucy Grealy says this very simply and beautifully: "Through [my friends] I discovered what it was to love people . . . It required the effort of always seeing them for themselves and not as I wished them to be."<sup>18</sup> Regarding how we respond to what the person shares, John Scott, quoting a physician who participated in his study of healing relationships, writes, "Be sure that you are responding to their problem and not your problem."<sup>19</sup>

How can I not think of Margaret? She is a wonderful teacher of the lessons applicable to the *space* stage of deep hospitality practice. Through her I have learned what little I know about giving the patient-stranger space to be herself, making space in myself to receive her different ideas and ways of being, and responding in a way that she identifies as helpful. What I have been unable to do is draw out her story, but maybe in that assessment of myself is another lesson she has imparted. Perhaps her story is not going to be revealed in a nice neat package delivered as a result of my skill at eliciting it, but instead has to be pieced together from her different ways of sharing.

We cannot discuss the practice of deep hospitality, especially in the *space* stage, without addressing the issue of boundaries, which is covered in the next chapter. And it is in the *space* stage that learning occurs, knowledge expands and wisdom increases; the intimate link between hospitality and education is addressed in chapter 11.

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Deep hospitality practices in the *space* stage:

Listen attentively

Be comfortable with silence

Open yourself to receive

Expect and welcome discovery, new knowledge, change

Attend to the person with unconditional positive regard

Recognize your inner stranger; be aware of judgment and sweep it away

Give the person what he or she wants, which might not be what you planned to give

Use meditation to connect with the person's humanity

Develop and use narrative competence

Implement facility procedures that promote narrative

Explore what the person wants to be clear about

Create a warm physical environment that invites feeling

## Chapter 10 – Boundaries

Ethical Principle: *Social workers recognize the central importance of human relationships.*

—Code of Ethics of the National Association of Social Workers

Although Margaret lives very close, we struggled to get her to the cancer center for her first treatment. Appointment after appointment she cancelled or just didn't show up. Following protocol, we sent a certified letter urging her to contact us to begin her life-saving cancer treatment, but even that didn't do the trick. I made a home visit, but she wasn't there—out shopping, her neighbor said. I don't recall what finally secured her commitment to treatment, but even then challenges remained. When it became clear that she had a problem with the bus company, their volunteer drivers, and the local taxi services, I finally decided to drive her myself. Walking into the cancer center together was a victorious moment, but before long the glow of triumph had been extinguished, when I was directed (by a VP, no less) *never* to personally drive another patient again; my job was to arrange transportation, not to provide it.

I haven't driven Margaret anywhere since then, but I have visited her home several times. I have gone to the pharmacy for her medication, paid the few dollars co-payment out of my pocket, and delivered it to her. I have sat on her stoop while she smoked cigarettes and ranted about her family. I have rested my hand on her arm and hugged her.

I have never called the people I work with “clients.” And although by necessity I refer to “patients,” I don’t care for the label. Instead, I prefer to think of them as “people.” Labeling draws boundary lines that identify individuals by their different pre-defined roles. The practice of deep hospitality requires health care professionals to reconsider what they have been taught about setting such clear boundaries between themselves and their patients. Sitting at table as equals and making space in yourself for the other’s story to change you are certainly line-blurring acts.

Twenty-eight years of working in a nursing home contributed to my boundary-defying attitude. I thought nothing of bringing 103-year-old Elsie home overnight at Christmas when her family wasn’t able to be with her. In nursing home culture at the time, that was something that earned you a pat on the back, not a slap on the hand. I accompanied people to weekend weddings and family reunions. We hugged and kissed and cried. I would have done just about anything to improve the quality of life for the people living in our nursing home. Imagine my surprise at being scolded for driving a woman with life-threatening cancer a half-mile to begin her treatment after a dangerous delay of many months!

When I began exploring the application of deep hospitality in cancer care, I decided to see what professional code of ethics might support my endeavor. To my delight, I found nothing in the National Association of Social Workers’ code that would prohibit a reasonable softening of boundaries. Indeed, I interpret “the central importance of human relationships” as meaning that most aspects of my work with a patient take a back seat to the quality of our relationship. “Social workers understand that relationships



between and among people are an important vehicle for change. Social workers engage people as partners in the helping process. Social workers seek to strengthen relationships among people in a purposeful effort to promote, restore, maintain, and enhance . . . well-being . . .”<sup>1</sup> Appropriate touch is permitted, as are dual or multiple relationships, such as being a social worker *and* a friend. The NASW code is an invitation to responsibly practice hospitality toward the other.

I also found support for my perspective from Frank Ostaseski, co-founder of the first Buddhist hospice in the U.S., who contends that we contribute to healing when we come out from behind our expertise and release ourselves from the limitations of our roles.<sup>2</sup> A leading promoter of rethinking boundaries is Rachel Naomi Remen, who writes extensively on this subject. In story after story she describes the danger of clinicians separating their humanity from their daily practice of medicine. When she was a young doctor, her supervising physician chastised her for crying with a grieving patient. She regrets having taken that lesson to heart for too many years. As a patient, despondent over her own life-limiting disease, she found hope and comfort when her doctor held her hand and offered his companionship through her difficult journey. “In fourteen minutes he had lifted the loneliness that had separated me from others and from my own strength. In some way that I didn’t understand then, this made all the difference.”<sup>3</sup> Remen writes of colleagues who cease to find meaning in their work or who “burn out”—not because of emotional attachment to their patients but because of emotional separation from them.

People who are physicians have been trained to believe that it is a scientific objectivity that makes them most effective in their efforts to understand and

resolve the pain others bring them, and a mental distance that protects them from becoming wounded by this difficult work. It is an extremely demanding training. Yet objectivity makes us far more vulnerable emotionally than compassion or a simple humanity. Objectivity separates us from the life around us and within us. We are wounded by that life just the same; it is only the healing which cannot reach us. Physicians pay a terrible personal price for their hard-won objectivity. Objectivity is not whole. In the objective stance no one can draw on their own human strengths, no one can cry, or accept comfort, or find meaning, or pray. No one who is untouched by it can really understand the life around them either<sup>4</sup>

To better understand healing relationships in primary care, researchers from several U.S. universities and hospitals conducted a study of the practices of exemplar healers. The discussion of the results includes assurances to any who are concerned that intimate relationships between practitioner and patient “might interfere with the detached concern required for the best diagnosis and treatment.”<sup>5</sup> They found no evidence of this and felt their results suggested the opposite: healing relationships result in better diagnosis and treatment.

While the practice of hospitality in cancer care calls for the subjectivity Remen describes, most professionals who are generous with their compassion would agree that some boundaries are needed. It behooves those whose vocation is caregiving to thoughtfully establish boundaries that balance the need for intimacy with the other with the need for self-preservation. Miroslav Volf proposes *porous boundaries* that work like an embrace.<sup>6</sup> When we embrace someone, we open our arms, close them, then open them

to let the other go and be ourselves again. Porous boundaries allow us to learn and be enriched by the other without losing our identity.

In imagining her body as a vessel where she holds a space of healing for those she loves, Terry Tempest Williams resolves,

I must also learn to hold a space for myself, to not give everything away. It reminds me of the Indian teachings of Samkhya: If you consciously hold within yourself three quarters of your power and use only one quarter to respond to any communication coming from others, you can stop the automatic, immediate and thoughtless movement outwards, which leaves you with a feeling of emptiness, of having been consumed by life. This stopping of the movement outwards is not self-defense, but rather an effort to have the response come from within, from the deepest part of one's being.<sup>7</sup>

Arthur Kleinman refers to the challenges of expressing intense empathy while keeping an appropriate distance. "The ethnographer does not seek to go native . . . but rather he struggles to learn to see things the way natives do, to enter into their experiential world."<sup>8</sup> Philosopher Jacques Derrida asserts that true hospitality does not involve assimilation or "simply the occupation of my space by the Other. . . . That's why it has to be negotiated at every instant, and the decision for hospitality . . . has to be invented at every second with all the risks involved, and it is very risky."<sup>9</sup> But while all of these writers and thinkers urge caution, they also acknowledge the absolute necessity of providing hospitality to the other.

A practitioner and her patient have to work out where the lines get drawn in their relationship. There are ethical and legal rules of conduct that must be followed; beyond that there is much discretion. Margaret does not call me at home and we are not best friends. I don't loan her money for her many overdue bills. If she dies before I do, and that is quite likely, I will cry and will speak at her funeral, but my world will not be shattered. Another social worker, nurse or doctor might have closer or more distant relations with Margaret than I, and I would not presume to judge the appropriateness. Besides, while compassion calls for getting personal, the practice of hospitality is not so much about erasing tangible borderlines as it is about moving the well-established lines drawn in our minds and hearts. As Henri Nouwen counseled, it is there we need to make space for receiving the stranger. It is there the risks and the rewards occur.

## Chapter 11 - Educare

To be inhospitable to strangers or strange ideas, however unsettling they may be, is to be hostile to the possibility of truth; hospitality is not only an ethical virtue but an epistemological one as well.

—Parker Palmer, *To Know As We Are Known*

*Educare*, the root word of “education,” means to lead forth the innate wholeness in a person. So, in the deepest sense, that which truly educates us also heals us.

—Rachel Naomi Remen,

*Kitchen Table Wisdom: Stories that Heal*

I knew Ernie for only two weeks, his last two. Shortly after he was hospitalized, I visited him to introduce myself and let him know about cancer support services. His wife was his sole visitor, and she couldn't come every day because they didn't have money for the gas. (Now there was something I could *fix*, and I did.) Ernie allowed me to be my curious self; I liked asking him for stories and he didn't mind telling them. We enjoyed our visits and when his wife and I were there at the same time, we made a jolly threesome, despite his very serious cancer. Responding to my inquiries, they told childhood tales and then the story of how they met and eventually landed in Vermont. In our first meetings, Ernie said he wanted to do everything possible to prolong his life because he had some things he shouldn't leave undone. As the days passed and the stories

of his life were shared, there was a hint of regret and apology about some of his wildness. Gradually he expressed less interest in holding on to the present; he reached a point where he no longer cared about seeing his dog again or worried about how his wife would manage after his death. Eventually his only wish was to die. Physical suffering had replaced emotional suffering. In talking with him about the most important aspects of his life, I believe I helped draw out of him an understanding of his life's disappointments and accomplishments that, along with his physical decline, readied him for a final release.

When Rachel Naomi Remen tells of talking with patients, listening to their stories and being present with them in their suffering, she refers to *educare*. Remen, Parker Palmer and others value the elemental sense of education represented by the word's Latin root: drawing out the learner's truth. It is instructive to compare this Latin verb with a related one, *docere*, which is the root of "doctor" and means to teach or show, implying an imparting of knowledge by an expert. Hospitable health care practice is about *educare*, because it involves drawing out, in the service of healing, what is within the patient-stranger. Remen takes it a step further: drawing out the patient's truth to lead the patient forth into healing.<sup>1</sup> But it is not only the patient-stranger who learns and heals when we draw out her truth in the *space* stage of hospitality practice. As previously discussed, patients and practitioners, in a continual exchange of guest and host roles, are both teachers and learners.

Parker Palmer, among others, reminds us of the intimate relationship between hospitality and education. Welcoming and making space for strangers and strange ideas—that is, practicing hospitality—is necessary in the exploration for and discovery of

truth. Palmer writes of this primarily in the arena of education, but it is entirely applicable to the provision of health care. When we address illness, cure and care, we seek knowledge and truth, at least as much from the one receiving the care than from the one providing it. Unless a patient-stranger shares information about himself, the practitioner learns nothing that will assist her to care for the patient. When sharing his story, the patient teaches the practitioner not only about this patient but also enables learning about other patients. And, as I experienced with Ernie, the patient can make a quilt of meaning out of the patches of his life's experience.

Palmer identifies three crucial elements of a learning space: openness, boundaries and hospitality. Openness means removing the obstacles that “we often create . . . to evade the challenge of truth and transformation.”<sup>2</sup> This is the same challenge that is present in all situations calling for hospitality. We often hold fast to what we believe to be the truth and we erect barriers to resist anything that might shake that truth and change us. Having our truth questioned is threatening.

Cara came to see me when her husband, diagnosed with three different cancers in a matter of days, decided to decline all allopathic care in favor of alternative treatments. His healing plan included leaving the state to reside near his birth family thousands of miles away and resuming involvement in the conservative Christian church of his childhood. He left Cara behind to take care of the house, the animals and herself on her meager monthly Social Security payment. During their many years together, Cara and Gary have lived a non-traditional, close to the land lifestyle, so “alternative” was nothing new to her. But Gary's behavior was outside of the box Cara held as truth. She was

shocked that after decades' long rejection of formal religion he would return to such a conservative faith tradition. She was stunned that he would leave her. Are they still a couple, she wondered? Is this only temporary? How can he be so unconcerned about their home, family and life in Vermont? Will he die sooner as a result of his choices? And without her? Luckily, practicing hospitality came natural to Cara. She did not agree with Gary's choices and she was hurt by them; but she opened herself to that which was true for Gary since he was diagnosed with cancer. Acting compassionately in the face of his suffering and her own, she listened attentively to Gary's new narrative which, on the surface, seemed to exclude her, and she found a path. I received an e-mail from her thanking me for my help and informing me that she was going west for the winter, to be with Gary.

Parker's second element of a learning space is boundaries. To add to the discussion of boundaries in the previous chapter, I propose considering the rules of moral conversation as a structure that makes possible the sharing that leads to learning—in a cancer center as in a classroom. In his classrooms Robert Nash asks, “How can we construct a framework for moral conversation that encourages the full and honest expression of many truths in one group?”<sup>3</sup> That framework is not “anything goes” (for example, adversarial discourse and one-upmanship are out), but rather a genuine dialogue for mutual understanding that abides by a golden rule: “Willingness to find the truth in what we oppose and the error in what we espouse, before we presume to acknowledge the truth in what we espouse and the error in what we oppose.”<sup>4</sup> Applying such a rule to a traditional healthcare setting, where there is a clear line between the one who holds the



knowledge (the wise practitioner) and the one who receives the benefit of it (the ignorant patient), and where science is the knowledge most valued, would enrich the learning that occurs there.

In his discussion of hospitality as the third essential element of a learning space, Palmer notes the good that comes from welcoming strangers and their strange ideas. He goes a step further, advising that we make room in the learning space for the expression of feelings (especially fears), reinforcing an understanding that we are not just welcoming the stranger in body and mind, challenged by his physical needs and different ideas, but we also welcome the stranger's feelings. This is another version of Nouwen's poverty of heart, in which we make space for others' feelings.

One important reason to create a learning space in cancer care is that we cannot do the work we love without the patient's story. When we fail to communicate to our patient that we are open to his truth, he will feel silenced, and while we might get the *data* we need to treat, we will not hear the stories through which truth is spoken. Frank addresses this eloquently.

What most ill persons say about their illness comes from their physicians and other medical staff, not from themselves. The ill person as patient is simply repeating what has been said elsewhere—boring second-hand medical talk. . . . Ill persons have a great deal to say for themselves, but rarely do I hear them talk about their hopes and fears, about what it is like to be in pain, about what sense they make of suffering and the prospect of death. Because such talk embarrasses us, we do not have practice with it. Lacking practice, we find such talk difficult.

People then believe that illness is not something to talk about. They miss the opportunity of learning to experience it with another.<sup>5</sup>

For this very reason, Charon encourages physicians to develop narrative competence. “If the physician cannot perform these narrative tasks, the patient might not tell the whole story, might not ask the most frightening questions, and might not feel heard.”<sup>6</sup>

Through patient stories we also learn about the experience of illness and suffering we will encounter in ourselves one day. A patient’s story is unique, but it illuminates the universal; hence, it has something to contribute to our lives and those of future patients. From Ernie I learned about fear and courage, and how to endure suffering. In his counseling work, Carl Rogers found that “hidden in all of the personal communications which I really hear there seem to be . . . aspects of the same order we find in the universe as a whole. So there is both the satisfaction of hearing this person and also the satisfaction of feeling one’s self in touch with what is universally true.”<sup>7</sup> Our patients’ stories may also lead to discoveries about ourselves. In writing about patient narratives, Blickem and Priyadharshini refer to “‘discovery learning’ . . . the stories provide material for readers to learn on their own, things the teacher does not yet know.”<sup>8</sup> Dorothy Owens would undoubtedly agree. “Hospitality also opens up avenues of discovery of something new and the invitation to view the world from a different perspective. A stranger may not simply challenge but ‘transform’ the physician through the attention given to the stranger’s ‘otherness’ and may elicit wonder and awe in the presence of the holy, the unfamiliar and the unexpected.”<sup>9</sup>

Even as I promote the practice of deep hospitality in cancer care and encourage the use of hospitable practices, I am aware that some patient-strangers are so demanding of time and emotional energy, and so unwilling to meet the most reasonable expectations, that our goal becomes to complete the treatment and send the person on her way. Rafael Campo acknowledges this challenge while addressing the value of patients' stories.

Our patients' stories too, if only we could listen to them less critically and cynically, might similarly inspire us to the more practically important discoveries of what truly ails them. Yes, we must always be wary of the ways in which the interlocutor may lead us astray; the possibility of violation of the narrative contract, that implicit agreement between us that the story being told is truthful and offering in the service of best care, is a real one. A patient in distress may speak to us across a chasm so vast that what we hear is terribly distorted—by our own professional distance, by our own most unprofessional fears and misapprehensions, and by society's attitudes which inescapably contextualize our every action.<sup>10</sup>

As someone who is still working to shake off a lifelong habit of judging, I love this pep talk. I have encountered that vast chasm, and Campo's advice is a reminder to empty my mind of its fixed ideas and my heart of its fixed emotional responses to make room for that which the patient-strangers and their stories can teach me.

Referring to the biblical commandment to love the stranger, Rabbi Jonathan Sacks stated, "We are *enlarged* [emphasis added] by the people who are different from us."<sup>11</sup>

This is a wonderful image for the learning and growth that can take place in the

relationship between caregiver and patient-stranger. Stoller reminds us, however, that this enlargement should not be restricted to individuals. He believes that our stories about cancer should be accessible to a wide audience for discussion in relation to social realities. Doing so leads to wisdom, which he calls “the knowledge that enables us to live well in the world.”<sup>12</sup>

Where *hospes*—an interplay of stranger, guest and host—meets *educare*—the drawing out of the learner’s truth—both the provider and the patient-stranger experience healing and gain wisdom.

## Chapter 12 – Grace

Elton John sang to Diana, and he was right: “You were the grace that placed  
Itself where lives were torn apart.” Could we be that? Could we be the grace that  
placed itself where lives were torn apart?

—Forrest Church, *Love and Death*

“Can you do this job?” Tom asked me. I had spent the last hour of work watching  
videos on the website of the Kenneth B. Schwartz Center, which trains and supports  
caregivers in the art of compassionate health care. When I got home, I directed him to the  
website and asked him to play “Leon’s Story.” As we listened to it, I cried for the second  
time that day.

Leon was an alcoholic street person when health care worker Kendall reached out  
to offer him services. The Schwartz Center videotaped Leon and Kendall talking about  
their relationship.<sup>1</sup> “The best sign that he’s sincere and that he’s a good caregiver,” Leon  
said of Kendall, “is I was on my deathbed in the hospital—they said my last rites and  
everything—and I looked down and who’s on their knees next to my bed? It was him . . .  
It brought me to, brought me back.” Kendall recounts that at one point in their  
relationship, they each said “I love you” to the other. It was all very moving testimony,  
but the line that really tugged at my heart was this from Leon: “I finally feel like a human  
being. I don’t feel like an animal. I don’t feel like I gotta be this certain kind of person,

intimidating. I can just be me; me ain't that bad, you know?" Leon's testimony was an unpolished version of Carl Rogers' take on empathy. "[It] dissolves alienation. For the moment, at least, the recipient finds himself or herself a connected part of the human race."<sup>2</sup>

I couldn't help but think of tough guy Bobby. After a seventeen-hour surgery, followed by three emergency surgeries in rapid succession, he was in an induced coma. He had no family or friends nearby to visit. I stood by his bedside and spoke prayerfully to him. To be honest, I don't know whether I was concerned about his living or dying; I just felt that Bobby deserved to have someone care enough to be present reverently. Bobby's face and neck were a mess from having the cancer removed and the area reconstructed, and I was thankful that much of the damaged part was covered with bandages. I can't claim to understand Emmanuel Levinas' sophisticated concept of connecting with the face of the Other, but at that moment it came to mind. The face that communicates defenselessness and a plea: Do not kill me. "Witnessing is bound to the fact that 'the face of the other' awakens a responsibility and a wish to care for him. Being a witness entails being able to see the other and admit what his face means, by facing him in his vulnerability."<sup>3</sup>

My seven-year-old grandson said of his two-year-old sister, who was sleeping in my arms, "She's so cute when she's asleep." I told him that he and his sisters are all cute when they're asleep, and every night they're with me I tiptoe to their beds just to look at them. That was the way I was watching Bobby. The coma was an unlikely refuge both for him and those who cared about him. Bobby abuses drugs, squanders opportunities and

exploits people; he is an outlaw. The coma provided him protection from pain and the chaos of his daily life. For others, it was a respite from disgust, frustration and passing judgment. To connect with his sleeping face was to affirm his humanity—not only his flaws and transgressions but also the part of him that is the Creator’s work of art.

Vulnerability is a powerful humanizing agent.

Not long after watching “Leon’s Story,” as I was telling Tom another cancer tale, he asked again, “Are you sure you can do this job?” “Yes!” I responded. “I’m the right person for it.” I’m convinced I am, but I’m not sure how. How is it I can get close enough to strangers to make a difference to them but not be devastated by their suffering and, often, their deaths? It might be all those years in the nursing home, where I came to accept death as natural. It might be that there are limits to my emotional investment; I can get personal without attaching. And how can I be the right one for the job when I have relatively little firsthand experience with fear or a sense of being lost and in a strange place? It’s true that experience provides an instant source of connection; that’s why so many providers of cancer support services are cancer survivors. But the *door, table, space* model of hospitality is a way for anyone to connect with the stranger arriving in cancerland. I’m not Rachel Naomi Remen with a history of life-threatening illness and all the right things to say to elicit responses that contribute to healing. But I can open the door with warmth and kindness, invite the person to sit at table as an equal, and make space in myself for the person’s story, accepting the person as he or she is. Remen is the first to avow that this contributes to healing, too.

As a result of the observation and reflection required by this thesis study, I am making progress in all aspects of the practice of hospitality, even silence. When I was sixteen my neighbor and church school teacher, Mrs. Titterton, bought me a small handmade banner at the church fair. It said, “May I be calmer, gentler, quieter.” I was surprised and took her gift as criticism. I had always been energetic and boisterous; it was part of my being. Over the years, friends have affirmed this characteristic; one favorite greeting card from a friend contains a quote from French writer Emile Zola: “If you ask me what I came into this world to do I will tell you: I came to live out loud.” Recently I had been mourning the loss of that favorite personality trait. I felt it disappear with the move to cancer care and I wondered if it were ever coming home. Perhaps, though, it’s not really gone. Perhaps I have just become a better listener. I need to remind myself what I learned about integrity a year ago: I am more than one thing. I can live out loud *and* be a gentle, quiet, attentive presence with persons in cancer care.

“Margaret is so good for me,” I told Tom one evening after visiting her at her apartment. “She forces me to let go of trying to fix things—because she doesn’t allow anything to be fixed. With her I get lots of practice just being quietly present.” Every once in a while I’ll offer Margaret a solution to one of a multitude of problems, but I’m not invested in it. She can take it or leave it and I’m unperturbed. I just stay, and I’m starting to like being there.

Remen is describing who I am becoming when she writes about a certain kind of silence. “The sort of silence that is a place of refuge, of rest, of acceptance of someone as they are . . . Silence is God’s lap. Many things grow the silence in us, among them simply



getting older. We may then become more a refuge than a rescuer, a witness to the process of life and the wisdom of acceptance.”<sup>4</sup> But Remen cautions that it is not only the suffering patient who needs refuge but everyone in the presence of that suffering.<sup>5</sup> Terry Tempest Williams, while caring for her mother, who eventually died of breast cancer like several other women in her family, reflected on this need for refuge and concluded, “My refuge exists in my capacity to love.”<sup>6</sup> Love, or its professional relative, deep caring, is a refuge for those willing to take the risks. Many who write about caring relationships in medicine emphasize the courage it takes to be a witness to the patient’s experience, to stay with that person even when the road ahead is unknown. Arman writes of the “abyss” related to the risk of facing mystery and uncertainty; being the patient’s companion on the journey makes the caregiver vulnerable to suffering, fear and death. However, the rewards of love and peace, and, as discussed in the previous chapter, discoveries of truth and meaning, are life-changing.<sup>7</sup>

Mrs. Titterton moved into a nursing home when she was 62 years old. Our families were no longer neighbors so we didn’t know all the details, but my mother heard that she had alcohol-related dementia. I recently discovered that she died in 2008 and the obituary included an expression of the family’s gratitude for nine years of professional caregiving. It also listed her extensive community service, evidence of her concern for people and the world. I’ve been imagining Mrs. Titterton in that nursing home, hoping that her companions for the journey were friendly and convivial, but also calm, gentle and warm—and quiet enough to listen attentively to her story.

Margaret continues on *her* journey, and she has learned that her remaining life is measured not in years, but in months and maybe only weeks. Like her own unfocused and scattered self, her cancer has spread out messily, littering other places in her body. Recently Margaret and I actually worked on an issue. We made a phone call together and tried to solve a problem. While she was distracted with the call, I studied her, noticing her funky dollar-store glasses and her even-colored long reddish hair. I observed that she was uncharacteristically maintaining her concentration and I felt sad, because that change in her may relate to something grievous happening in her brain. For a moment, I breathed her in and held her in my heart. And a moment later we were back to discussing the overdue bill.

Forrest Church asks if we can be the grace that places itself where lives are torn apart. Grace is about as abstract as a word can be; theologians can debate its meaning endlessly and still not have anything tangible to offer the masses. But it's a concept worth mulling over. One way to understand it is as an unearned gift or blessing, given not because of who we are or anything we did but strictly out of love. Hospitality is grace. When we practice deep hospitality in cancer care, we open the door to one whose life is torn apart with a cancer diagnosis. We don't do this because of anything we know about the person, who is a stranger to us; we do it out of care for the other and we do it because at times in our lives we, too, are strangers hoping for a hospitable welcome. In practicing hospitality, we offer companionship for the portion of the patient-stranger's journey that winds through our land, sharing suffering and vulnerability, map and compass, walking side-by-side to a place familiar and secure. We make space in mind and heart to receive,

know, accept and learn from that stranger by our quiet presence and by drawing out and listening to stories that contain the truest truth. When we do this, we are a refuge and the grace that contributes to the healing of woundedness—that of the patient-stranger and, now or someday soon, our own.

## Notes

### Chapter 1

1. Wisenberg, *Adventures*, 115.
2. Mouw, Tippett interview.
3. Frank, *At the Will*, 48-49.
4. *Ibid.*, 14.
5. Stoller, *Stranger in the Village*, 200.
6. Frank, *At the Will*, 122.
7. Paget, *Complex Sorrow*, 7.
8. Charon, "Narrative Medicine," 1898.
9. Stan Mack referred to cancerland when writing about his wife's breast cancer, from which she died. A former cartoonist for *The Village Voice*, Mack litters his book with cartoons, humor and poignancy. About the recurrence of Janet's cancer he wrote, "We were back in cancerland and speaking its language."  
Reporter Mike Celizic, dealing with lymphoma, wrote a series for about TODAYShow.com entitled, "Adventures in Cancerland." Mike Celizic, "Adventures in Cancerland, Part 1: the Diagnosis," msnbc.com, [http://www.msnbc.msn.com/id/31526935/ns/today\\_health/](http://www.msnbc.msn.com/id/31526935/ns/today_health/) (accessed October 18, 2009).  
Breast cancer survivor Barbara Ehrenrich penned a scathing article for Harper's Magazine called "Welcome to Cancerland."  
Alysa Cummings wrote about how Breast Cancer Awareness Month (each October) "has a way of putting my CancerLand experiences on instant replay." Alysa Cummings, "In the Name of Pinkness," The Abramson Cancer Center of the University of Pennsylvania, <http://www.oncolink.org/blogs/index.php/category/greetings-from-cancerland/> (accessed October 18, 2009).  
Kris Carr, director of the film "Crazy, Sexy Cancer," compares herself to "Alice in Cancerland." Talha Burki, "Alice in Cancerland," *The Lancet Oncology* 8 (July 2007): 585-586.  
In her poem, "Mammogram Blues," Constance Alexander refers to "Lois Lane in Cancerland." / By day a simple rewrite girl, / at night a breast investigator." Constance Alexander, "Mammogram Blues," *American Journal of Nursing* 100 (July 2000): 39.
10. Corrigan, *Middle Place*, 266.

### Chapter 2

1. Genesis 19, *Bible*, NRSV.
2. Murray, *Do Not Neglect Hospitality*, 26.
3. Ibid.
4. The Abraham story is found in Genesis 18. While there are individual tales of hospitality in the Old Testament, there is also one central saga that informed the spiritual practice. Israel had its beginnings in God requiring Abraham and Sarah to leave their own land to become strangers in a foreign land. The “chosen people” were intentionally made strangers, sojourners, aliens and refugees. When God gave the people commandments and laws through Moses on Mt. Sinai, among them was this one: “You shall not oppress a resident alien; you know the heart of an alien, for you were aliens in the land of Egypt” (Exodus 23:9, *Bible*, NRSV). In his last instruction to the Israelites before they entered the promised land, Moses reminded them that God “loves the strangers, providing them food and clothing. You shall also love the stranger, for you were strangers in the land of Egypt” (Deuteronomy 10:19, *Bible*, NRSV).
  5. Thompson, *Soul Feast*, 120.
  6. Hebrews 13:2, *Bible*, NRSV.
  7. Matthew 25, *Bible*, NRSV.
  8. Luke 14:12-14, *Bible*, NRSV.
  9. John 4:5-29, *Bible*, NRSV.
  10. Luke 10:38-42, *Bible*, NRSV.
  11. Homan, *Radical Hospitality*, 37.
  12. Ibid., 74.
  13. Ibid., 36.
  14. Westfield, *Dear Sisters*, 113.
  15. Ibid., 81.
  16. Ibid., 113.
  17. Homan, *Radical Hospitality*, 109.
  18. Nouwen, *Three Movements*, 102.
  19. Ibid., 103.
  20. Ibid., 105.
  21. Miroslav Volf, “Identity and Otherness in a Fractured World,” St. Michael’s College, Colchester, VT, March 31, 2008.
  22. Nouwen, *Three Movements*, 107.
  23. Rosello, *Postcolonial Hospitality*, 167.
  24. Owens, *Hospitality to Strangers*, 26.
  25. Nouwen, *Three Movements*, 93.
  26. Ibid., 95.
  27. Homan, *Radical Hospitality*, 213.
  28. Ibid., 51.

### Chapter 3

1. Nash, *Liberating Scholarly Writing*, 19.
2. Remen, Interview by Tippett.
3. Palmer, Interview by Tippett.

4. Vanier, Interview by Tippett.
5. Palmer, *To Know as We Are Known*, 109.

#### Chapter 4

1. Aung, M.D., "Loving Kindness."
2. Dartmouth-Hitchcock Medical Center, "Finding the Words," 23.
3. O'Donohue, Interview by Tippett
4. Miller, *Cancer Poetry Project*, 20.
5. Ehrenreich, "Welcome to Cancerland," 44.
6. Remen, *Kitchen Table Wisdom*, 64.
7. Homan, *Radical Hospitality*, 215.
8. Dartmouth-Hitchcock Medical Center, "Finding the Words to Say It," 6.
9. Jean Vanier, Interview by Krista Tippett.
10. Hanh, Interview by Tippett.
11. Beach was involved in a Johns Hopkins study published a year earlier, examining the effects of dignified treatment, in which respect is defined as treatment with dignity. M.C. Beach, et al., "Do Patients Treated With Dignity Report Higher Satisfaction, Adherence, and Receipt of Preventive Care?" *Annals of Family Medicine* 3 (2005): 331-338. Another study: Janice Blanchard and Nicole Lurie, "R-E-S-P-E-C-T: Patient reports of disrespect in the health care setting and its impact on care," *The Journal of Family Practice* 53 (2004): 721-730. Correlation between patients' perception of lack of respectful treatment and the same patients receiving suboptimal care.
12. Homan, *Radical Hospitality*, 190.
13. Quoteland.com, [http://www.quoteland.com/author.asp?AUTHOR\\_ID=456](http://www.quoteland.com/author.asp?AUTHOR_ID=456) (accessed November 20, 2009). Another popular version is attributed to Edward Everett Hale: "I am only one. I cannot do everything, but still I can do something; and because I cannot do everything I will not refuse to do the something that I can do." ([http://www.quoteland.com/author.asp?AUTHOR\\_ID=1298](http://www.quoteland.com/author.asp?AUTHOR_ID=1298)).
14. Coulehan, "Insulated from Contagion," 165.

#### Chapter 5

1. CUREMedia, *Extraordinary Healers*, 29.
2. Lorde, *Cancer Journals*, 25.
3. Stoller, *In the Village*, 98.
4. Frank, *At the Will*, 27.
5. Taylor, *Cancer Monologue*, 42.
6. *Ibid.*, 56.
7. Rieff, *Swimming in a Sea*, 35.
8. Frank, *At the Will*, 10.
9. Lorde, *Cancer Journals*, 49.
10. Stoller, *In the Village*, 1.
11. Wisenberg, *Adventures*, 36.
12. CUREMedia, *Extraordinary Healers*, 12.

Terrified: “The news was terrifying.” (Olga Ogooussan), CUREMedia, *Extraordinary Healers*, 51. “My cancer diagnosis instilled in me a terror I thought only I could know.” (Paula Kruse), *Ibid.*, 104.

In a nightmare/dream: “I want to write of the pain I am feeling right now, of the lukewarm tears that will not stop coming into my eyes—for what? For my lost breast? For the lost me? And which me was that again anyway? For the death I don’t know how to postpone? Or how to meet elegantly? I’m so tired of all this. I want to be the person I used to be, the real me. I feel sometimes that it’s all a dream and surely I’m about to wake up now.”<sup>7</sup> (Audre Lorde), *Cancer Journals*, 23.

Isolated: “Silenced, we become isolated in pain and the isolation increases the pain. . . . Darkness compounds the isolation and loneliness of pain, for the sufferers are separated from those whose bodies lie quiet. In darkness the world of those in pain becomes unglued, incoherent.” (Arthur Frank), *At the Will*, 30.

Not special: “She had the death that she had anticipated having, when, just after she was diagnosed, she had said to me, “This time I don’t feel special.” Of course, none of us is special. . . . And yet feeling special is part of what makes us human. (David Rieff about his mother, Susan Sontag), *Swimming in a Sea*, 156.

“The leveling of distinctions troubles me. It’s a sign of devaluation. My sense is that cancer patients need to be valued more rather than less, need to be supported more rather than less. Almost everyone, really, needs more care, attention, and respect.” (Marianne Paget, commenting on the infusion room), *Complex Sorrow*, 109.

“Today a young woman came to my house and interviewed me. I was disappointed that all the questions were fill-in-the-blank, multiple choice, or true/false. What about my unique story?” (S. L. Wisenberg), *Adventures*, 73.

On a journey: An article about research on healing relationships in primary care begins with this lovely line. “Wild azaleas bloom in my garden each spring, reminding me of the botanist who gave them to me and our journey through his suffering and eventual death from prostate cancer.”(Scott, “Understanding Healing Relationships,” 315).

## Chapter 6

1. Frank, *Wounded Storyteller*, 3.
2. CUREMedia, *Extraordinary Healers*, 104.
3. Taylor, *Cancer Monologue Project*, 16.
5. Taylor, *Cancer Monologue Project*, 98.
6. Sontag, *Illness as Metaphor*, 68.
7. Frank, *At the Will*, 51.
8. *Ibid.*, 186
9. Zola, *Missing Pieces*, 206

Lost without a map: “I had fallen off the map, the world, of the knowable. I had fallen out of space, and out of time, too.” (about an episode of serious illness, although not cancer). (Oliver Sacks), *Leg to Stand On*, 110.

“The following days [after diagnosis], my family was numb and lost. (Leanne Bartlett), CUREMedia, *Extraordinary Healers*, 53.

A new world, a foreign land: “How can a nurse recognize that the world of cancer care is a foreign world to patients and caregivers and set about making it familiar enough to manage?” (Joan Raducha) *Ibid.*, 120.

“In March 2001 I learned that I had lymphoma, one of several kinds of blood cancer. Having enjoyed more than fifty years of good health, I was used to living my life in the village of the healthy, in which illness is a temporary nuisance that is quickly and completely cured. Cancer suddenly introduced me to the village of the sick, in which illness becomes a continuing condition for which there is usually no cure.” (Paul Stoller), *In the Village*, 1.

“Illness is the night-side of life a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.” (Susan Sontag), *Illness as Metaphor*, 3.

A foreign language: “Some of her [Susan Sontag’s] notes on various doctors . . . highlight the impossibility of a nonscientist making sense of much if not most of what she was being told . . . Even my mother, so supremely confident in her own ability to ‘work up’ subjects and master information, found herself incapable of following what she was told. I felt much the same way, as if I had suddenly found that I had become a functional illiterate. There was all this information, but it was in a foreign language *and*, when translated, it generally turned out to be bad news.” (David Rieff), *Swimming in a Sea*, 83.

“The pathology report is full of mysteries, and in the exam room the surgeon says, Do you have any questions?” (S. L. Wisenberg), *Adventures*, 46.

“I’d like to know what a ‘core needle’ is, but I’m more interested in why he’s ‘concerned.’ He says the mass is quite large, perhaps seven centimeters, and looks like an *explosion*. That’s the very word he chooses.” (Kelly Corrigan), *Middle Place*, 24.

The foreignness of battle: “People with other diseases are just plain sick; those with cancer ‘fight’ it. . . . Newspaper stories that refer to poverty, crime, and drug abuse as ‘cancers’ reflect society’s attitude toward cancer as the dreaded other. Against this other, combat is the only appropriate response. But I do not believe illness should be lived as a fight.” (Arthur Frank), *At the Will*, 83.

“As long as so much militaristic hyperbole attaches to the description and treatment of cancer, it is a particularly unapt metaphor for the peace-loving.” (Susan Sontag), *Illness as Metaphor*, 86.

A stranger unto oneself: “With each chemotherapy treatment I experienced a loss of my sense of self. This disconnection extended to my family and friends. I felt like an alien in my own body.” (Lena Albert), Taylor, *Cancer Monologue Project*, 41.

“The stories that ill people tell come out of their bodies . . . The body is often alienated, literally ‘made strange,’ as it is told in stories that are instigated by a need to make it familiar.” (Arthur Frank), *Wounded Storyteller*, 3.

“I can never accept this, like I can’t accept that turning my life around is so hard, eating differently, sleeping differently, moving differently, being differently. Like Martha said, I want the old me, bad as before.” (Audre Lorde), *Cancer Journals*, 10.

“I’ve worked here twenty six years, but I feel like it’s my first day on the job, like I’m the stranger.” (Harvey Pekar), commenting on someone taking his job while he was sick with prostate cancer. *Our Cancer Year*, 1.5.

Alien invasion: “Given the militaristic metaphors that are utilized to categorize the “war” on cancer, it is not uncommon for people to think of malignant cells as alien invaders, as not part of the body, or to use A. David Napier’s phrase, as ‘non-self.’” (Paul Stoller,), *In the Village*, 211.

Colonization: “In becoming a patient—being colonized as medical territory and becoming a spectator to your own drama—you lose yourself. First you may find that the lab results rather than your body’s responses are determining how you feel. Then, in the rush to treatment, you may lose your capacity to make choices, to decide how you want your body to be used. Finally, in the blandness of the medical setting, in its routines and their (57) discipline, you may forget your tastes and preferences. Life turns to beige. It is difficult to accept the realities of what physicians can do for you without subordinating yourself to their power. The power is real, but it need not be total. You can find places for yourself in the cracks. I want to affirm the importance, both for yourself and for those around you, of holding onto the person you still are, even as medicine tries to colonize your body.” (Arthur Frank), *At the Will*, 56.

“I felt like an object, a piece of baggage that had been misplaced. Sitting in Waiting Room 4 for hours dehumanized me. I had quickly learned the true meaning of the word *patient*. Considering medicine as an institutional system, ‘Patients’ must be ‘patient,’ for they have few rights and limited importance. Waiting at the hospital for my CAT scan-guided biopsy, I felt very much like a colonized subject.” (Paul Stoller), *In the Village*, 51.

The liminal state of remission: “Sometimes fear stalks me like another malignancy, sapping energy and power and attention from my work. A cold become sinister; a cough, lung cancer; a bruise, leukemia.” (Audre Lorde, 18 months after breast cancer surgery), *Cancer Journals*, 13.

## Chapter 7

1. Roth, *Sweat Your Prayers*.
2. Easwaran, *Like a Thousand Suns*.
3. Stoller, *In the Village*, 43.
4. *Ibid.*, 22.
5. Becki Jeffe in CUREMedia, *Extraordinary Healers*, 38.
6. *Ibid.*, 29.
7. Remen, *Kitchen Table Wisdom*, 150.
8. Jegen, *Just Peacemakers*, 36.
9. Miroslav Volf, “Identity and Otherness in a Fractured World,” St. Michael’s College, Colchester, VT, March 31, 2008.
10. Jegen, *Just Peacemakers*, 32.



11. Zola, *Missing Pieces*, 73.
12. Grealy, *Autobiography of a Face*, 31.
13. Frank, *At the Will*, 52.
14. Sacks, *Leg to Stand On*, 46.
15. Ibid.
16. Frank, *At the Will*, 67.
17. Grealy, *Autobiography of a Face*, 138,

#### Chapter 8

1. Scott, "Understanding Healing Relationships," 320.
2. Stoller, *In the Village*, 43.
3. Paget, *Complex Sorrow*, 23.
4. Rieff, *Swimming in a Sea*, 135.
5. Zola, *Missing Pieces*, 229.
6. Frank, *At the Will*, 69.
7. Updike, *Self-consciousness*, 46.
8. Remen, *Grandfather's Blessings*, 146.
9. Frank Ostaseski, lecture at Dartmouth Hitchcock Medical Center, October 29, 2010.
10. Another example is found in Williams, *Refuge*. "Mother was given instructions to change into the hospital's blue and white seersucker robe. They say the gowns are for convenience, so they can do what they have to do fast. But their robes seem more like socialistic wraps that let you know that you belong to the fraternity of the ill waiting patiently in rooms all across America." 26.
11. Frank, *At the Will*, 26.
12. Ibid., 27.
13. Inui, "Hello Stranger," 417.
14. Remen, *Kitchen Table Wisdom*, xxxviii.

#### Chapter 9

1. Remen, *Grandfather's Blessings*, 218.
2. CURE Media, *Extraordinary Healers*.
3. Remen, *Kitchen Table Wisdom*, xxix.
4. Spiegel, "Narrative Imperative," ix.
5. Stoller, *In the Village*, 112.
6. Frank, *At the Will*, 14.
7. Remen, *Grandfather's Blessings*, 156.
8. Charon, "Narrative Medicine: A Model," 1899.
9. Rogers, *Way of Being*, 143.
10. Lorde, *Cancer Journals*, 46.
11. Frank, *At the Will*, 56.
12. Stoller, *In the Village*, 70.
13. Inui, "Hello Stranger," 415.
14. Frank, *At the Will*, 13.

15. Ibid., 14.
16. Charon, "Narrative Medicine: A Model," 1897.
17. Kleinman, *Illness Narratives*, 232.
18. Grealy, *Autobiography of a Face*, 195.
19. Scott, "Understanding Healing Relationships," 318.

#### Chapter 10

1. National Association of Social Workers Code of Ethics, National Association of Social Workers. <http://www.naswdc.org/pubs/code/>
2. Frank Ostaseski, lecture at Dartmouth Hitchcock Medical Center, October 29, 2010.
3. Remen, *Grandfather's Blessings*, 162.
4. Remen, *Kitchen Table Wisdom*, 78.
5. Scott, "Understanding Healing Relationships," 321.
6. Miroslav Volf, "Identity and Otherness in a Fractured World," St. Michael's College, Colchester, VT, March 31, 2008.
7. Williams, *Refuge*, 168.
8. Kleinman, *Illness Narratives*, 230.
9. Derrida, "Politics and Friendship."

#### Chapter 11

1. Remen, *Kitchen Table Wisdom*, 325.
2. Palmer, *To Know As We Are Known*, 71.
3. Nash, *Religious Pluralism*, 172.
4. Ibid., 178.
5. Frank, *At the Will*, 4.
6. Charon, "Narrative Medicine: A Model," 1899.
7. Rogers, *Way of Being*, 8.
8. Blickem, "Patient Narratives: The Potential," 624.
9. Owens, *Hospitality to Strangers*, 26.
10. Campo, "Anecdotal Evidence," 1678.
11. Sacks, Interview by Tippett.
12. Stoller, *In the Village*, 200.

#### Chapter 12

1. Schwartz Center, "Leon's Story."
2. Rogers, *Way of Being*, 151.
3. Arman, "Bearing Witness," 85.
4. Remen, *Grandfather's Blessings*, 164.
5. Ibid., 137.
6. Williams, *Refuge*, 178.
7. Arman, "Bearing Witness," 86.

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