

# A Compass for the Cancer Journey: Scientific, Spiritual, and Practical Directives

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How might their lives be different, because there is a nurse to whom they turn? A nurse who helps them learn to light a candle, a nurse who helps them accept and trust their limitations, rebuild their strengths, and know, in the dark of winter, that their energy will return like the spring (adapted from Duerk, 1989, p. 103).

The legacy that continues through the Mara lectureship is a wonderful gift. In preparation for this presentation, I reflected on my 31-year career in cancer nursing, the thousands of patients I have had the privilege to care for, and the journey that has led me to this place. It is a long way from a childhood in Kansas. Who would have thought my journey would unfold in this way? It has been a wonderful journey, with lots of hills and valleys. I am so proud to be an oncology nurse.

I chose the compass imagery for directives because I believe each of us develops in our profession with the mentoring direction of others, some internal drive or motivation, as well as our intellect and compassion. We also give direction to our patients and their families. Many patients have described their experience with cancer as a journey. Thus, the compass metaphor seemed quite fitting and worth reflecting on as I recalled stories from my practice—the challenges, joys, and fears of patients and family members as they had told their stories to me. The stories of patients are as I remembered them, and many others came to visit my heart as I prepared for this presentation. It was a gift to remember the parts of their journeys that we shared and what they had told me about finding their way. Although I am a scientist, an advanced practice nurse, and sometimes an educator by professional position, education, and experience, this presentation was prepared simply, completely, and passionately from my grounding as an oncology registered nurse. These stories are part of my professional journey, from my intentional and sometimes unintentional wanderings, and as such, this is very personal. Hopefully this will be personal for each of you in some way. Every oncology nurse has a great deal to say about nursing, because you have cared for patients, walked with patients and their family members, and perhaps have done the same for your own family members and friends. Some of you reading this have walked the cancer journey yourself. You have

encountered obstacles along the way, as well as made new discoveries, and often met these with knowledge, wisdom, great integrity, and great vision. Sometimes you have traveled in broad daylight and sometimes with only a dim light to guide you. Sometimes you have been successful; sometimes you have met with disappointment. I imagine that you have grown with the experiences or you would not be reading this article now. Or perhaps you are curious how what you read here might enhance your journey as an oncology nurse. Gustafsson and Fagerberg (2004) reflected that nurses experience situations where courage is needed. Nurses take risks, occasionally testing methods, procedures, or acts that are new territory for us.

The purpose of this article is to affirm the significant contributions of oncology nurses to the well-being of people with cancer and their families, through stories representative of the cancer journey, a journey moving toward healing and wholeness. Because my professional practice for the past 20 years has been only in breast cancer, much of this article will reference these experiences. I trust however that these stories will speak to you no matter what your practice area includes. Thus, as you read the stories that follow, reflect, reminisce, or let your thoughts drift to new ideas. Contemplate and see yourselves reflected in the stories or recall your own. Reflect for a moment on where you have been in your journey as an oncology nurse, where you are now, and what your future holds. Draw your own conclusions about what a compass for the cancer journey means to you and to the patients and families you serve.



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May “something unacknowledged [be] brought into [your] consciousness” (Moffitt, 2004, p. 70).

Take advantage of the reflective practice questions included here. My hope is that, after reading this article, you will feel ever more strongly the significant role you have as a nurse in cancer care; how valuable you are in scientific, spiritual, and practical ways; and how and where you bring light to another’s path.

A compass circle, or rose, is 360°, and the cardinal directions are 90° apart, with other directions in between (Jacobson, 1999).

The compass is a device to give direction in the outer world, but to use it as a metaphor in describing the cancer journey, it is necessary to learn a little about it. We need to understand a little more about the science behind it, the parallel meaning behind finding one’s direction or way in life, and the practical uses of it. Of course, first, one needs to know the four main directions: north, south, east, and west.

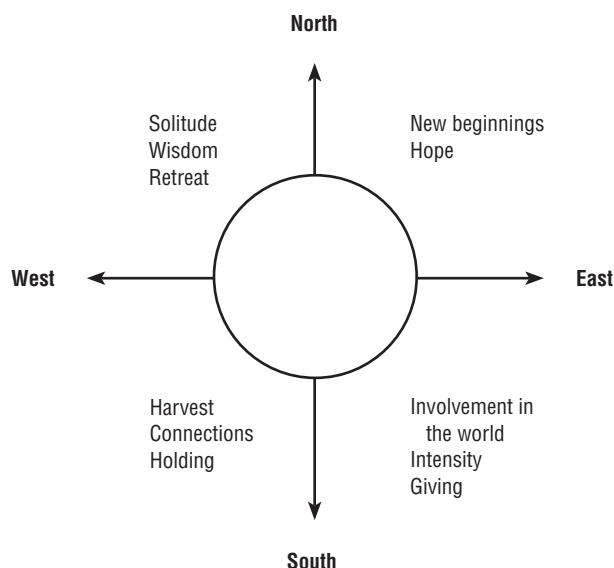
Native Americans and other ancient civilizations had sacred circles, often made of many stones carefully laid out on the earth, as symbolic representations of the circle of life, of the four directions, of wholeness, and of cycles that have beginnings, ends, and new beginnings. For example, to Native Americans, the south symbolically is associated with the season of summer (Four Worlds Development Project, 1988) (see Figure 1). This is an active and intense time, of involvement in the world of work and family and living. If we liken this to hiking, a serious hiker knows that making a new trail is hard work. If in dense growth, it might take a machete to cut through brush. The hiker is creating a new trail, and it will

not be until the final destination is reached that the hiker will know he or she was on the right path. The west is figuratively associated with autumn. The hiker has reached the clearing in the brush and sees the journey was in some way necessary and rewarding. In some ways, this is like the process patients go through when transitioning from completion of treatment to long-term follow-up. It is a time of harvest, completion, and letting go. It can be a time of “not knowing.” In the north is winter, where one rests in the clearing and prepares to go out again. It is the nighttime, the dream time, the time of mystery, hibernation, solitude, regeneration, and wisdom. Many women describe wisdom they have gained through their breast cancer journey. This wisdom is integrated into their lives in such a way that many will be able to share it with others on similar journeys. Nurses do this, too. Symbolically it is in the north where this occurs. As the seasons continue, to the east is spring, reawakening, new beginnings, and hope. Perhaps our first professional experiences as oncology nurses or in new roles in oncology, or a person’s resolve to do everything he or she can to survive cancer are illustrations of this aspect of our journeys.

These are just conceptual examples of a symbolic compass or cycle of life. As ancient and modern wisdom tells us through these symbols, the journey is ongoing and a process that needs our regular attention. A compass is, in common understanding, something external to ourselves, in nature, yet man-made from one’s understanding of the physical laws of the universe and the unseen—trying to make the unseen more manageable, so to speak. A compass must be learned; it is not a natural device, although on the surface it looks obvious and logical. How is a compass also internal to the individual? A friend said he learned how to use a compass when he was a Boy Scout, and the hardest thing about learning how to use it was not when he was in an unknown place but when he was in a familiar place and the landmarks and understandings he had of his environment did not match the compass readings. When logic says one thing and the compass says another, how do you trust the compass? How do you trust yourself? Sometimes we need an external compass, something that guides and directs in the outer world; often, we also need an internal compass.

### Reflective Practice Question

How have you guided someone on his or her cancer journey? How have you been guided?



**Figure 1. Compass Points**

*Note.* Based on information from Bankson, 2005; Four Worlds Development Project, 1988.

One might think of a journey with cancer as having a beginning, a middle, and an end. One hopes for long-term survivorship, although that will not be true for all. No journey, as we know from our understanding about grief, is necessarily orderly or neat or successful. Yet most of us would prefer it to be so. The cancer journey is also not linear. It is often a circuitous process, and it evolves over time.

Learning about a compass has provided us with a very simple idea of what we see happen for women with breast cancer. Breast cancer and all that goes with it is the last thing in the world a woman wants to understand. There is way too much to learn, and it feels like one could never master anything about it. The cancer experience is an emotional landslide. Which compass provides direction in this type of a situation? Despite

this, most women do seem to master the landslide—or at least most aspects of it. This awareness, gained from observations of breast cancer survivors over years of practice, helps me as a nurse impart this confidence to women newly diagnosed with breast cancer, to help them know with some certainty that they will make it past this landslide. In some way, as a nurse, I am serving as an external compass, giving a little direction, however briefly.

When someone faces a diagnosis of cancer, there is no map for how to proceed. Even if an external compass is available for part of their journey, through family, friends, spiritual beliefs, or the healthcare team, many individuals have trouble finding their way and need many landmarks and way points and guidance in finding the right compass. The mountain looms large ahead. The specific features one looks for in a compass can be likened to what nurses provide, such as versatility, speed in unstable conditions, accessibility, and durability, as well as the ability to offer light in the dark, and even the ability to aid in reading the fine print (see Table 1).

**Table 1. What You Need in a Working Compass**

Compass Features	Nursing Features
Versatility: ability to translate readings at checkpoints to actual path	Patient and family educator and support person
Speed of operations in unstable conditions	Efficiency, preparedness
Carry ability: lighter, more compact, with rounded edges, best	Accessibility
Durability: built to take everything from a bad fall to drenching rains	Strength, not afraid, caring
Compatible with you	Compassionate and empathic
Compensates for environmental changes	Recognizes sociocultural and environmental aspects of care
Has features that offer light in the dark	Embraces hope
Magnifying glass (to help read the fine print)	Reads between the lines; listens actively

*Note.* Based on information from Jacobson, 1999.

It's easy getting from point A to point B "if you have a systematic plan and a compass. The important thing is to keep track of where you are *all the time*—easy enough if you [make note of] checkpoints along the way and reaffirm your position at each point" (Jacobson, 1999, p. 36).

I would like to share some stories, and the first one is about Patricia<sup>a</sup>. Here is a part of her journey.

For Patricia, as for many women, the breast cancer journey started not in shock and anger but in sheer terror of the unknown, in anticipation of the end of life as she knew it, of the end of the world. I was asked to speak with Patricia because she had called her surgeon requesting a prescription for severe anxiety while she waited for her biopsy results that were scheduled to arrive the next day. I called her at home and told her who I was (a registered nurse working with her surgeon who asked me to call because of her anxiety). I said I understood she had had a biopsy the day before and was returning the next day for results. She was so very scared that it would be cancer—the surgeon had said it did not look good. In Patricia's mind, she already had cancer. Her surgeon probably had a good idea about the results, but did she *really* tell Patricia it did not look good or is that what she heard? I could not tell from the mammogram report. It was a routine mammogram, she said, and every year she dreaded it, because her sister just went through breast cancer treatment a year ago; her husband's first wife and mother died of breast cancer. It was so hard on her stepchildren and her sister's children. It would be so hard on her own children, she said. And she did not want to worry her husband. She slept poorly and feared she would drive her husband crazy. Was he that vulnerable? I wondered. The night before, he had to tell her he needed to get some sleep or he would not be able to take care of her. He said he **WOULD** be there for her, but he needed some sleep! She could not see beyond her own concerns about how she

would get through this if it was cancer. She had not been able to go to work that day because of her anxiety, so she was sitting at home. She had done all the laundry and the ironing, watered the garden, and paid the bills, not sure she actually signed or dated the checks in the envelopes, now sealed. She talked to her neighbor about some community event but did not remember now what was said or even really participating in the conversation. When her neighbor had asked her if something was wrong, she replied, "No, I'm OK." She talked to her priest, too.

I suggested how good it was that she had been faithful to her regular screenings and that she was able to have the biopsy and get results before the weekend. It was Thursday when we spoke. She said if only she had waited until Monday, she would have a better weekend. She had not been breathing well; a short while before, she thought she was starting to hyperventilate. "It's important to b-r-e-a-t-h-e," I told her. I told myself the same thing. I heard her on the other end of the line following my suggestion to take a deep breath in and slowly let it out, letting the anxiety go out and the relaxation come in. She was silent as I heard her breathing slowly in and out. She thanked me for listening and asked if I saw people privately. We agreed a little medication for her anxiety was probably a good thing. I told her I would see her the next day when she got her results. I called the surgeon with my assessment; we agreed a small dose of an antianxiety agent was in order, and that is when the surgeon told *me* she was sure Patricia's lump was malignant.

I recalled a discussion with a colleague, a marriage and family therapist, who cosupervised a group of volunteers with me. At our previous session with the volunteers, she told the group that anxiety is *imagining* being chased by a lion in the jungle; fear is *being* chased by a lion in the jungle. No safe haven, no check points, no landmarks. I began to anticipate Patricia's response to the news of her diagnosis the next day and reflected on how many times nurses have waited for results of biopsies and been present as the physician disclosed those results. Sometimes it was cancer, sometimes not. It is not just the diagnosis of breast cancer that our patients face. This lion will be with them always, although we hope he will be tamer. The lion likes to roar before every follow-up appointment, just as a reminder of his presence. The question

<sup>a</sup> All stories are representations of actual events; names and details have been changed to protect privacy and confidentiality.



is how all of these experiences will be integrated into the patient's life. How will each woman LIVE?

That evening as I was having dinner with my husband at our favorite local Italian restaurant, I noticed people coming and going and thought of Patricia, at home with her husband, maybe calmer now on medication, yet waiting for what I had already been cued to believe was the inevitable. She believed it, too. We had talked of calming and distractions, yet I would have a very hard time, also. A diagnosis of breast cancer. You just do not think it will be you. You hope it will never be you. Across the room, I noticed a familiar face, Nancy, a breast cancer survivor and Reach to Recovery volunteer. She would be a panelist at a volunteer training I was to do soon. Nancy was diagnosed well over five years ago, quit smoking, ran a marathon, and still plays golf. It was a life-changing event for her, she had said. She got healthier in many ways. That is how her journey unfolded. She wanted to give to others some of her human light and kindness. Patricia, meanwhile, was at home, waiting to learn that she would begin this journey. Fearing the worst, afraid for her children and husband, her stomach in knots, her mind scattered, and her sleep restless; that night, at age 52, she was living with more uncertainty than she had ever known. No compass, no direction, no light.

Sylvia, age 60, another breast cancer survivor, said that patients like herself do not articulate their feelings about their nurses and their cancer experience very well, and then she proceeded to do so. She said that when she was "slammed against the wall" with her diagnosis, the nurses helped pick her up and gave her some of their power. "I still feel that when I go back to my oncologist's office," she said.

Other women described what they felt was most important in their breast cancer journey. At age 41, Leanne, an oncology nurse and mother of young children, said she felt it was most important to her, as a patient, that nurses and other healthcare providers stayed open minded to what was of concern to patients. She thinks we need to just stop and listen. She also pointed out that breast cancer truly can affect any one of us—oncology nurses included. She added that nurses need to realize the impact that cancer has on a woman's sense of well-being and the sense of loss that accompanies it.

Pam said she "benefited by such good care at the time of diagnosis—follow-up on issues, a lot of compassion and support, a lot of explanation of the process—that all worked really well for [her]." Alena said, "If you don't take humor on your trip, you won't make it." Her husband and her sense of humor kept her focused and sane. A nursing colleague and breast cancer survivor, Teresa, said she was most upset by the lack of information on hot flashes. "This is my fifth year of hot flashes!" she said, adding that she had been prescribed a low dose of an antidepressant that was still unopened in her medicine cabinet because she did not like to take anything unless she had to.

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**"Because nurses have never had the prerogative of omnipotence, we find it comfortable and natural to be with the patients as human beings, without social distance" (Diers, 2004, p. 202).**

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Getting back to Patricia, I met her and her husband before she met with her surgeon. The antianxiety medication had helped a little bit, and she had slept during the night. I was

with another patient when the surgeon gave Patricia her results. The surgeon told me later that she took it very well. I thought to myself, she already knew, in her gut. She had lived with it for 48 hours. I went in with the RN who would teach Patricia about breast-conservation surgery and sentinel lymph node biopsy. Patricia sat quietly on the examination table, teary-eyed, tremulous when she spoke, looking very small as an adult woman, yet composed. Her husband sat nearby, and shortly after our brief review of what had just happened and their joint expressions reflective of their anxiety, they began asking very organized and specific questions about the surgery: how it was done, when it would be, when radiation would start, when it would be over, when would chemotherapy start (she hoped never), how this would affect their sex life (her husband asked that question so easily, I thought), how they did not want to tell the children of her diagnosis. We listened to each question and tried to answer according to their unspoken need for more or less information. Patricia's husband asked for reading material for spouses, and Patricia asked what she could read. We suggested she not focus on reading as she had enough anxiety already; she laughed in response.

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### Reflective Practice Question

Who is the recipient of my care? How have I exhibited scientific, spiritual, and practical caring behaviors recently? What is a memorable story from my career?

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She said she felt her anxiety was relieved being there with us and wanted to take us home with her. Her husband said he was reassured when the surgeon said Patricia would not die from her breast cancer. Of course it was not out yet, but it did appear to be quite small—invasive, yet very small. We were confident and calm. Perhaps a little bit of it rubbed off. Afterwards, the RN and I reflected on our interaction with Patricia and her husband. We felt good about the couple's interaction, and we felt good about ours with them. We each felt so badly that she had so much anxiety. However, we each could see a lot of inner strength, which, by the husband's testimony, was always there for others, but now Patricia needed to apply it to herself. What will be her path? From where will she find direction and light for her journey? And what or whom will be her landmarks?

The scientific directive supports preoperative education as an intervention that reduces postoperative anxiety. The practical directive guides nurses to deliver this in a form and language that are useful to the individual; the spiritual directive guides nurses to open the door to discussions about spiritual and support strengths and needs before and after surgery. Diers (2004) said that "nursing done right is physically, emotionally, and intellectually fulfilling. Many people think nursing is simple. . . . But to be caring, to deliver tender loving care, is exquisitely difficult" (p. 158).

Several authors have described caring behaviors of nurses, and I have added my own (see Figure 2). Giving theoretical information (e.g., explaining what is normal) also means giving scientific and factual information so that a patient and family can make informed decisions. Providing physical comfort can include such actions as holding another's hand, touching, or covering with a blanket. Holding the mind, body, spirit connection for patients and family members means looking

- Giving theoretical information (what is normal)
- Being present, having patience, and listening attentively
- Providing physical comfort
- Being honest
- Being responsible
- Showing sensitivity and respect
- Supporting the patient's power
- Projecting calm and confidence
- Holding the mind, body, and spirit connection for them
- Hearing their stories
- Bridging the disconnects

## Figure 2. Scientific, Spiritual, and Practical Caring Behaviors by Nurses

Note. Based on information from Barnum, 1998; Boyd & Munhall, 1989; Miller & Cutshall, 2001; Wolf, 1986.

at the whole person, living in the world as we each do, with scientific, spiritual, and practical needs. Nursing care requires us to integrate our hearts and our brains in such a way that we are ready to experience an authentic, human connection.

Kate and Amelia wanted us to know that it is not easy being in the prime of your young adult life and diagnosed with breast cancer. Breast cancer only happens to older women, right? Wrong. Amelia, at age 30, said at first she thought it was all going to be over soon and everything would return to normal. Then she realized it never would be the way it was before, ever again. That was really hard to get through. Yet she now knows you can be happy again—perhaps even happier and in more profound ways. She is. Meeting other young women like herself helped immensely, and those connections remain guiding lights now as she faces her third recurrence. Facing the family, being the adult and the child, dating, working, and making choices about having children, all are especially poignant issues for young women with breast cancer.

Kate was 28 when she was diagnosed. Her mother and grandmother had already been through it so she chose to have bilateral mastectomies. Kate made a short film about her experience (Buescher & Vecchione, 1998). In a memorable scene from the film, Kate runs into her boyfriend by the pool at her apartment. He apologizes for not sticking around for the biopsy. She replies, “Whatever.” He retorts, “I flipped, all right? Nothing like this has ever happened to me before.” Kate replies, “I won’t do it again.” When she asks him if he could sit down and talk for a few minutes, he says he has to go and hands her a matchbook with a photo of a seated toless woman, suggesting that when Kate gets herself “rebuilt” she might consider this woman’s build. He was a not-so-bright light on her journey. He did not stick around, and Kate moved on. Kate’s journey eventually led her to try skydiving, in celebration of two years passing since her diagnosis. Referring to the skydiving experience, Kate said, “It’s definitely the most powerful experience I’ve ever had. So was surviving cancer.” Kate just celebrated her 10-year disease-free mark.

Annette, at age 38, said the two most difficult things for her were losing her hair and telling her parents about her diagnosis. She was physically sick the night before she told them. On reflection, she recalled that her parents had left for Italy the day she had her routine mammogram and were to be gone two months. The same week she received her biopsy results, her parents returned home six weeks early, her mother saying she

just had a strong feeling that they needed to be home. They had no idea what Annette had been going through—at least not on a conscious level. “My mother broke down in tears and the color drained from her face when I told them; my father remained calm, composed, asking very specific and supportive questions, and reminded my mother that the cancer was found early,” Annette said. They served as a compass for her.

Annette’s parents went with her to each chemotherapy treatment. During that time however, her dad, an ex-military man, turned into putty, soft as a lambskin glove, and her mother was as solid as a rock. Annette said, “I was their little girl, and he couldn’t take care of me and make it better.” Seeing this switch in her parents was amazing for Annette. The firm grounding and direction her mother gave her and the nurturing along the way given by her father enabled them to get through it together.

Regarding her hair loss, Annette said she first went online to research all about her chemotherapy. She read all kinds of things that *might* happen, and so she started thinking maybe they *would* not happen. The oncologist put it on the line for her though; knowing the definite really helped. Otherwise, she said, she would have still hung on to those little things. When her hair fell out, she was more prepared. She said she would have been more devastated if she had still been hanging on to that little shred of hope. One patient with a light of hope in her heart told me that when her hair started falling out, she went outside on her balcony and let her hair fly into the air by handfuls, knowing the wind would carry it to where a bird needed it for a nest.

Annette did not tell many people about her diagnosis because when she did, at first, they treated her differently. They started to cry, or they acted like she had been given a death sentence. She said that now she is a much stronger person so if people acted like this with her again she would tell them directly how unsupportive their responses felt.

Knowing who to talk to, letting people in, shutting others out with good protective social boundaries, trusting, and experimenting all require energy and time which sometimes are in short supply. With a confidante, a soul mate, a friend, a peer, a colleague, a close companion, or perhaps someone who has been through a similar experience, words sometimes are unnecessary.

Kate, mentioned earlier with her former boyfriend, lived on the West Coast and her parents lived in the Midwest and were afraid of flying. Kate wanted someone near when she was in the middle of chemotherapy. In her film (Buescher & Vecchione, 1998), Kate appears in her home in the morning, without hair, in her pajama bottoms, and with a towel draped around her neck, talking to herself about choosing to get well *every moment*, answering her own questions out loud. “Will I wake up today?” “Yes.” “Will I keep my breakfast down?” “Yes.” She reflects further out loud that all she really wants is someone who understands what she sees in the mirror. Her mother walks into the room. She had taken the train to be with Kate. Her mother then removes her robe to reveal her own mastectomy scars, and as Kate reveals herself to her mother and they hug, she says to herself, “Am I the daughter of warriors?” “Yes.” This was a landmark moment for each of them.

Yukea, at 67, recalled her journey with breast cancer when she came into the clinic for a checkup. She brought cookies to thank the staff for their care and to celebrate her five-year mark. She wanted to express that one of the most important things for her in getting through her breast cancer and treatment was having a focus point. She met another woman while

going through radiation who told her that there is always a light at the end of the tunnel. For Yukea, this became her focus point, or landmark, as well. "As long as I came back to that thought, I was okay," she said. "I prayed a lot, too." It was grounding for her, a return to center.

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For water travel, "some of the best sources of river conditions are the people who live [there]. Always check with them before embarking on a river, even if you've [done] it many times. Be aware, however, that locals tend to exaggerate the dangers of their river. So [also] seek out . . . professional people who work in the area" (Jacobson, 1999, p. 55).

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Yukea said that having the same nurse there each time she came back for a visit was very supportive, because she knew the nurse cared and made a special point to see her each time. She said,

When I was pregnant, they taught us how to breathe. I had to remind myself many times during breast cancer treatment to breathe—to slow down and breathe—because I wasn't breathing. My body was doing everything off schedule and out of pattern. Sometimes I was up, and sometimes I was down. My husband was great. My friends were great. Sometimes I just needed someone other than them to talk to who didn't judge me and who could listen unconditionally. And I needed a focus point. I had to learn all this.

We all have a desire for something we can depend on, something that is a constant. We need meaning and purpose internally, a true north, an internal compass so to speak, yet we also need the guidance of external landmarks along the way to help us mark our progress. As nurses, we often provide this to our patients.

I asked my nursing colleague and dear friend of 25 years, who is also a 17-year breast cancer survivor, about her personal and professional journey with breast cancer. Vicky, age 57, recently went back to work as a hospital staff nurse. She said going back to work after all she had experienced has allowed her to see she has a more solid appreciation for what patients are going through, the pain they endure, and the dependent role they assume. On her breast cancer journey, hope was her guiding light, often revealed in interactions with such people as an oncology nurse and a breast cancer survivor and the confidence she felt in her oncologist and surgeon. She spoke of how vulnerable a woman feels after the diagnosis. In the hospital, as her friend and a breast cancer nurse, I sat with her, held her hand, and tended to her spirit as well as her physical needs. At home, I did some of the same. What she remembers to this day is that the nurses and support staff in the hospital never offered her a washcloth. The chemotherapy nurse had some kind of business on the side and talked about it a lot—it was very annoying. Vicky wishes now she could have been able to tell her that. She would have liked the nurse to talk with her about current events or something to distract her. Vicky's advice to nurses is to not be afraid to approach patients, even if they are surrounded by family or friends. Even if they appear to not need you, approach them, she said. LISTEN for what they need and want.

She described a breadth of positive and negative experiences, some of which persist even now. Memory loss was and still is a problem, and going into menopause was a big shock. Acquaintances and friends would call on the premise of checking on her but ask too many questions or just be nosy. "It is very hard not to talk to people you don't want to talk to," Vicky said. Church friends provided a never-ending supply of home-cooked meals for her family. Lack of knowledge made her want to withdraw, so she sought as much information and advice as she could. Today she still lives with unsatisfactory reconstruction. She intentionally avoids looking in the mirror. The first set of implants, which were later replaced because of capsular contracture, is in her dresser drawer. She is contemplating more reconstructive surgery but has decided against it for now because of all that is involved with no guarantee of good results.

Vicky often cares for patients from foreign countries or other states and cities, because her hospital gets many patients in the midst of journeys of their own, having experienced health crises during flights into a regional airport. She recognizes they are in a strange environment as well as physically ill. Her goal is to connect with each of her patients in some way. She described this so well.

When I come onto shift and I walk into a patient's room, I can pick up a vibe from them. They are waiting for me. They may not be conscious of it, but they are waiting for me. Many people can interact with a patient but not connect. My goal is to connect. How often will we attend the dressing or the IV but not the person? These things should not be our first stop. Not to say that you don't have to do those things. Yet patients are hungry for a connection.

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"A connection links two or more, formerly separate, entities in a meaningful way with one another" (Holtorf, 2001).

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Vicky told the story of an older adult woman admitted for back pain, who had a large and partially ulcerated breast mass. The patient told Vicky, "Why should I do anything? I'm too old!" Vicky then sat down with the patient and actively listened to her story. Vicky recalls, "She looked me straight in the eye and thanked me for my time, for the opportunity to talk openly with someone who seemed to care so much." It took about 15 minutes. When Vicky returned to work two days later, she learned the patient had decided to have treatment that might control the local disease. Vicky told me, "In some way, I think our talk helped her make that decision. I realize now my intervention wasn't complete though. I didn't write a note in the chart about our talk. No one would know what we did together unless one of us told them. And it was an important intervention."

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"Nursing is so personal a service, so private an experience, so invisible alone in a room with a patient that no one will ever know it fully except the individual nurse" (Diers, 2004, p. 202).

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Every time we meet a patient, are we looking for a way to connect? Do we have the *intention* to connect? How does the patient (or family member, student, or colleague) know we are *really* listening?



The spouses or partners of women with breast cancer have additional responses and concerns. Vicky's husband, Dave, remembers feeling like he had been kicked in the stomach when he found out. All he could think about as he drove into the hospital's parking lot was that his mother had died there five years earlier from metastatic breast cancer. He didn't think anything could have prepared him for what he and Vicky experienced. He needed information in plain English: what was going to be done to his wife, why, when, and where, and how he was going to take care of her. He was not prepared for how exhausted she would be after the surgery and during the chemotherapy. He admired her strength.

An advanced practice nurse and colleague from radiation oncology often says that when she sees a woman for initial evaluation after surgery, she is aware of the woman's partner and how the couple interacts. She said, "I notice if they are holding hands, if she is reading a magazine, if he is pacing." She said she is not sure as nurses we are always consciously aware of all we observe about patients and their family members. When a partner says, "We had chemotherapy before surgery" or "We are concerned about side effects of radiation," she makes herself stop and look at both of them and says, "Do you know how good that makes me feel to hear you say that? It tells me that you are in this together." She said that usually they look at her with so much appreciation that someone has noticed them on *their* journey, validating *their* coping as a couple. In my practice, I also now intentionally try to notice and be mindful of the partner or caregiver. Perhaps I have learned to see and hear the partner who, earlier in my career, I was less able to see or hear. Communicating this, being present in an authentic way, is scientific, spiritual, and practical.

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*"When I dare to be powerful, to use my strength in the service of my vision, then it becomes less and less important whether I am afraid" (Lorde, 2007).*

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Once I spoke with a couple about a treatment plan for breast cancer. After about 45 minutes, the husband said, "I don't know how you do this." After a brief moment of reflection, I replied, "It is because of couples like you that I do this," and he began to cry. He said that initially he had not wanted his wife to share the diagnosis with anyone. He had come to realize, however, that by her sharing with others, they had now received a lot of support and good connections that were really helpful. I thought to myself, they are really very strong, but they just do not yet know it.

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### Reflective Practice Question

*When and how have I changed or found new direction with a patient, a family member, a student, or myself?*

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How are they? Do we ask, "How are *you*?" Sometimes the partner will say, "I am just fine. It is my wife I am worried about." I returned a call to the husband of a patient; both were in their late 70s. I knew from a previous interaction about my research study that his first wife had died of breast cancer and, as a couple, they felt that the additional support offered in my study was not needed because of their many

understanding friends. On that particular day, he was calling for information about a referral. He was organized in his initial questions, and I answered them easily. Yet I changed things when I asked him, "How are you doing?" There was a long silence on the phone. When he spoke again, his voice was tremulous. He said it was really hard—that he wanted to be strong for his wife and that he did not want to lose her. He did not want her to worry about him. Friends had been very supportive and that was helping. I listened and acknowledged his genuine concern. I was able to share my confidence and faith that the two of them together would get through this, to share my knowledge that his wife's breast cancer had been found very early, and to give my assessment that overall this was so very, very good. He responded and we talked a little longer. Before hanging up, he thanked me for hearing him and being present for him. I think we were mutually touched by the interaction. Recently they returned together for her annual follow-up and I made a point to see them, to say hello, and to see how they were doing. They said they were glad I remembered them. If he remembered our conversation, he did not acknowledge it, but that did not matter. They were doing well. I had been touched by the interaction and just wanted to reconnect. They remain a little light for me.

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*"What is invisible in any human service is the thinking behind the act. Nursing requires the use of all the visual, aural, tactile, and psychological senses; they detect the data upon which one acts" (Diers, 2004, p. 202).*

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Five years ago, Darlene, a 70-year-old art history professor, came into the office for a postoperative checkup. After her initial lumpectomy with my practice, she had gone elsewhere for a mastectomy and reconstruction because of her insurance. Glad to see me, she smiled as I escorted her into an examination room and said, "You are not going to believe this, but my breast is under my arm! And it's wrinkled!" She undressed and showed me. Sure enough, her expander was under her arm, at the side of her chest. Smiling, Darlene said,

Can you believe it? I think this is it. I'm just going to have someone take it out. I really don't need it. I'm okay with it. I saw the other surgeon because mine was on vacation and he was just as puzzled as I. He can't figure out how it would have happened. He said he would re-do it for me. I told him I just want it out, but I came here first to see what you think. I have to laugh though. What can I do?

A couple of months after the removal of her expander, Darlene called because she was thinking of getting a tattoo on her chest. She said she had told her surgeon her plans and he said, "Oh no, you'll get hepatitis, or HIV. . . . Why would you want to do something like that?" She had not yet heard of Deena Metzger, a Los Angeles poet and breast cancer survivor. Deena's well-known photo shows her standing in a field, arms outstretched, revealing her right-sided mastectomy scar with a tree tattooed across it. I told Darlene I had a coffee mug with Deena's photo from an American Cancer Society benefit that I would give her. She was thrilled. I received a postcard from Darlene a few months later. It read, "My first trip to the mountains since surgery brought winds of welcome

from my beloved mountains and quaking aspen trees jubilant in their golden dress of fall. The music within has returned. My cup goes whither I go, filled with gratitude." A year later, she wrote that she planned to get the tattoo, a swirling of green leaves and vine. She wrote, "The scar will not be considered a battle wound nor a mark of survival from war-making. Instead, I see the empty space as a canvas for creative expression." Her surgeon said he understood her now, her feeling of being out of balance, telling her, "My mother, who is about your age, had a mastectomy eight years ago and she feels exactly as you do." Darlene said she wanted to "drape herself around him in gratitude."

I called Darlene because I had not spoken with her in a couple of years. She is doing great. She brought over a picture of herself with her new tattoo so I could show it when I gave breast cancer talks. She had told me when she revealed the tattoo to her surgeon, his reaction was palpable, "It is so BOLD!" She researched what she would have tattooed and by whom, saying, "I didn't want to be embarrassed by an artistic failure." Her favorite colors, red and black, are the two colors in her tattoo. She wrote me a note that the tattoo is based on Japanese calligraphy and asked me to note how it connects to her remaining breast. She added, "It has no meaning." I disagree. What I saw was filled with meaning. She is traveling well, she has found her direction, and the path is secure.

What are your gifts? What kind of light do you shed on another's journey? How do you help patients and family members reach their way points? How do you help them connect? How do you help them learn to use a compass, map the path, and find the landmarks successfully, creatively, fully, and wholly? When you find something you are really good at, such as educating or listening, how can you incorporate that more into your cancer nursing practice? When are you stretched to provide the best possible care? What are you curious about? Are you curious about what you do not know? Are you curious about what you need to know to provide better scientific, spiritual, and practical care? How do you receive what patients or family members, colleagues, or students give you? How do you give of yourself?

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### Reflective Practice Question

How have I illuminated another's path? How has my path been illuminated?

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As an advanced practice nurse, I am often called in to speak with patients or family members when they are flooded with emotions and feelings and overwhelmed by the diagnosis or treatment plan. Sometimes the surgeon calls me because a patient is crying or extremely angry and being "unreasonable," asking the same questions over and over or threatening to have no treatment at all or use only alternative healing practices. I find out the surgical plan, the biopsy results that led to that plan, and what the patient was told. With the patient, my first goal is to connect with the individual, to be present. I sit down to equalize the relationship. If I sense it is appropriate, I touch the patient, either putting my hand on her shoulder, taking her hand, or just sitting closely. I acknowledge those present in the room with the patient. Find out who they are in relation to the patient. Let the patient cry if that is what she is doing. If she

says, "I'm OK, I'm OK," I say, "I know that. I am just here to be with you, to give you support as I can." If she says, "Who are you? Why are you here? They must think I am crazy!" I wonder if she feels crazy. I might even say that to her, depending on the situation. I tell her that I am a registered nurse with specialized training in breast cancer and was asked to see her "because the staff felt I would be especially helpful. And no, we don't think you are crazy; this is very, very difficult. If you weren't feeling this way right now we would be more concerned about you." It is so important to be able to allow people to feel what they are feeling and to express those feelings in a safe environment. It is also important for us to help a patient and family in processing the most difficult feelings, when they are ready.

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### Healing Presence

Someone "who can be silent with us in a moment of despair or confusion, who can stay with us in an hour of grief and bereavement, who can tolerate not knowing, not curing, not healing, and face with us the reality of our powerlessness" (Nouwen, 2004, p. 38).

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When I can, I find out how she is doing. Sometimes I get the obvious, "How do you *think* I am? Wouldn't *you* be feeling this way?" Usually I get more detail. I find out what patients understand about their diagnosis and treatment plan. I find out who they consider part of their network of support and communication (those present or those not present and what that means). Who or what are their checkpoints in the daily world they live in? What do they do for a living or how do they spend their time? (How will they *live* during and after breast cancer treatment?) I am connecting the dots, the checkpoints, the potential landmarks along each patient's future path so that I can be of better support and guidance.

What is their spiritual life like? Do they find solace and peace in any particular form? Are they involved in a church or temple? Do they have a spiritual connection through personal practice or formalized structure? What is their faith? Usually I get a very straightforward answer. As we talk, I come back to this again. Working in a Catholic institution, someone from the pastoral care department can be invited to visit with a patient, and I often ask more distressed patients or family members if they would like that. If not at that time, I ask the day of surgery or while they are in the hospital. Women of many beliefs have taken advantage of this offer and expressed gratitude for even considering that part of their lives. Ancient wisdom suggests the path or journey through life is one that returns again and again to center, to a place of being in the world with meaning. Whatever gives meaning to the individual and a reason for being in the world, whether formalized by one's faith tradition or religious affiliations, is what I consider spiritual, is vital to the journey, and calls out to be honored. This remains a core of my practice philosophy.

To really listen to another means to use more than just our ears. It means focusing, paying attention, understanding, allowing thoughts to penetrate our consciousness, hearing another's words and understanding the message, and asking, silently or perhaps out loud, what does the other person mean and what does the other person want from me during this encounter? Listening also means not having the ready answer while others are speaking.



Recalling Patricia, whose story I began with, the day before surgery, she returned to have a lymphoscintigram to map the lymphatic path to the sentinel node. Her husband looked tired, and his hair appeared to be uncombed. She did not want to hear much, yet she seemed to want reassurance. I started to speak and she stopped me short saying, "I don't want to hear anything." Later, after he was out of earshot, Patricia's husband asked if she had stage III disease because the tumor was 6 centimeters. In fact, her tumor was 6 millimeters. He had heard it incorrectly. Patricia asked if I could do a guided imagery relaxation session with her. I chose one about guiding yourself to a safe place. I explained the process, telling her to get into a comfortable position and concentrate on her breathing. Together we breathed slowly in and out. Then I guided her as she sought out a safe place in her imagination. I was giving her direction, but she was finding her own way. It only took 10 minutes.

One more story I want to share is that of Rosario, age 73. Because of her breast cancer experience, her creative artistic endeavors evolved to include beautiful images and colors that she could not see before her diagnosis. When I called almost two years ago, she told me that her cancer had returned. Sadly, her earthly journey ended last year. We had some very good talks about her life, her dreams, her hopes, her children and grandson, and her loving husband. We discussed her fatigue from fighting, her desire to let go, and her sadness at leaving the loves of her life. She was no longer afraid. She expressed that one of the most important things she felt all women need "is so very basic, yet so important . . . and that is kindness. To have a nurse around you who is kind makes a big difference for the patient," she said. "It is so simple, yet it's true. Having a kind attitude. That is it." Rosario suggested that we "encourage women to try and find a place within that helps them fight their fight." She wondered many times to herself, "How am I going to get past this FRIGHT and be ready to fight again? Sometimes I have to tell myself I'm going to get up and do this or that. Sometimes I draw and let my dreams take me away. I need hope."

This article contains a series of stories about opening doors and being present and aware of what we as nurses give to others and the gifts we receive. These stories illustrate small segments from the journeys of some of the breast cancer survivors I have had the privilege of knowing, whose stories called out to be told. The similarities, differences, complexities and simplicities of these journeys, meanderings, and lights along the way are important to remember. Think about your own journey as an oncology nurse, the lights and landmarks you know or hope for and where they have led or where you hope they will lead you in the future. Our perspectives are important and valued; we make a difference.

Many people have contributed to my journey as an oncology nurse, and I carry them in my heart wherever I go. In addition to family and dear friends, many colleagues in the Oncology Nursing Society have shared their professional as well as personal guidance, whether they realize it or not; the colleagues who nominated me for this award, Deborah Boyle, MSN, RN, AOCN®, Harold Freeman, MD, and Melissa Craft, PhD, RN, AOCN®, all are true glowing lights on my professional journey. Writing this has caused me to pause, ponder, and remember with fondness and deep appreciation the faculty members who first taught me how to

give a bed bath to an older patient, how to give an intramuscular z-track injection to a child (I do not know which of us was more terrified), and how to respond to a patient asking me if she was going to die. I also fondly recall the faculty member who required my class to listen to all of Elizabeth Kübler-Ross's, MD, audiotapes on death and dying and who coached me in providing an unconventional nursing intervention for a young man with schizophrenia. We all have so many stories to tell.

There is tremendous power, strength, and wisdom in people who face cancer, and it is often humbling to us as professionals. Likewise we see these traits in our colleagues. We mourn our losses, we rejoice in our successes. Developing a sense of hope and a perspective of balance in the face of cancer is a requirement to be able to give back in kind to patients and family members.

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*"You cannot be a healing presence entirely on your own. You need support and nurture" (Miller & Cutshall, 2001, p. 55).*

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Having colleagues in other fields with whom I have been able to discuss new challenges, such as when I found a woman who could only sit rocking herself in the lobby after learning her diagnosis, or communicating in another language or culture all the aspects of a new diagnosis of cancer—each of these experiences, when shared, has led to my being able to respond better and more expansively the next time.

Being in new territory can be very unsettling. At the same time, it can be very affirming. Responses such as "I am so glad you brought this up" or "I would be honored to spend some time talking with you about this" or "I don't know if I'm the best person to have this discussion with you because this is not my area of expertise; however, I will research this for you or provide you with a referral" each may be appropriate under different circumstances. We just need to listen and respond authentically and seek help and counsel where we need it. Case conferences for clinical supervision and debriefing, a common approach in mental health nursing but not in oncology nursing practice, are a formal method of helping to refine one's knowledge, get validation for one's responses, and hone new skills.

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### **Our Directives**

*Scientific:* to know the field—nursing science, medical and psychosocial sciences

*Spiritual:* to develop our personal sense of meaning and purpose, of spirituality, and resources for patients, families, and ourselves

*Practical:* to learn about local and international resources and develop connections; expand our worlds

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As oncology nurses, we are challenged today to stop, look, and listen to our patients, to their family members, to our colleagues, and to ourselves so that we can learn about the science of cancer treatment and cancer care and contribute to the science of oncology nursing. What is it we do that makes

a difference? How do we demonstrate that? How do we let others know? What are the acute and chronic side effects of treatment where nursing has the greatest impact? Many of these, first identified by patients, are first reported to nurses. What will we do with the information? And how do we balance the tensions between connecting and creating distance, between acting in a holistic way and acting in parts? We learn to balance the expression of emotions in a way that is supportive of another, including sometimes expressing our own sadness with patients or family members. We also learn how to receive the gifts that come from interaction with our patients (see Table 2).

We will continue to be challenged to understand and provide for many practical care needs of patients with cancer simultaneously. Spirituality is perhaps the least well-addressed aspect of the cancer journey in the literature. Yet our profession has always been committed to tending the spiritual along with the physical, emotional, and social needs of people with cancer. No matter which path we take, we each must look to those times when we were disappointed or when we labeled ourselves as unsuccessful to see what we can learn from those situations. Perhaps when we gave too much information and someone did not want it, we failed to recognize a new symptom as indicative of a treatment complication, we cut someone off when we told them it would be okay, or we did not take the time to recognize a colleague's grief.

Continued reflection is critical for understanding one's inner compass, one's true north, and one's personal and professional path. The stories of patients, families, and nurses reveal intertwined journeys of bringing light to each other.

Reflective Practice Question

What is my true north? What tools, maps, and guides have I integrated into my career and life paths? What is on my horizon?

Perhaps the following enchanted tale sums up the breadth and depth of scientific, spiritual, and practical caring by oncology nurses best of all.

Once upon a time, there was a young nurse. She was efficient, smart, well educated, and well groomed and considered a good nurse for her age and experience. She entered the room where Betsy waited for her to attend to her nursing care needs. Betsy did not know exactly what she needed, except that she needed a nurse to do it. Over the next 12 hours, the young nurse took care of the drains, helped Betsy learn how to do the same for herself,

Table 2. Tensions in Making Connections

Connect	Disconnect
Make a connection.	Create distance.
Act holistically (science, spiritual, practical).	Act in parts (science without spirit, spirit without science, science without practical).
Express positive emotions.	Contain negative emotions.
Give to the patient or family.	Do not receive from the patient or family.
Explore a new path.	Keep to the well-traveled road.

changed dressings, got Betsy extra juice, listened to stories of Betsy's family, talked to her about chemotherapy, guided her through exercises, gave her medications on time, requested the repair of a faulty radio control, kindly set a boundary on Betsy's behalf to limit time visitors lingered, and told Betsy's 10-year-old son that his mommy was doing really well, would be home soon, and missed him.

As she was leaving the room, Betsy called her attention to a small package on the table. It was marked "for you, my nurse." Betsy had told her not to open it until she was home. The nurse thanked her and was so very curious what was inside. It was light as a feather. It had a beautiful rose-colored silk ribbon around it. Just the package itself was beautiful.

"We tangoed through my problems and decision-making, letting me choose whether you would lead or follow. . . . You actively engaged the creative healer who was fighting to survive [and] made time to . . . help me heal—become whole" (Harpham, 2007, p. 49).

As the nurse sat down at home in her comfortable chair, she held the package in her arms. She reflected on her day. It had been so busy. She was so tired. She put her feet up and fell asleep for a while. When she awoke, the package was sitting on the floor next to her chair. She remembered Betsy. Betsy was in the hospital because she had a mastectomy and reconstruction for stage II breast cancer. She was 35 years old. So young to have breast cancer. The nurse herself was only 30. Betsy had moved to the United States from Belize at the age of 16, gone to college, and met and married her husband. She recently divorced, and her son was staying with her ex-husband while she was in the hospital. She had already gone through so much, thought the nurse. "I think she'll be okay, though," she thought.

The nurse then remembered the gift. Slowly she untied the silk ribbon, lifted off the lid, and saw a note inside from Betsy. It read,

You have given me something wonderful. Faith in myself. Faith in my journey. Faith in my recovery. It was your confidence in everything you did today that reassured me, calmed me, and gave me hope. You probably weren't even aware that you did all that for me. We didn't talk about it exactly. You explained what you were doing when you changed my dressings and emptied the drain tubes. You did it all so efficiently and confidently. You explained why I needed to take deep breaths. You explained how pain works and how to take my medicine so the pain is better controlled. I felt better physically despite everything! Yet most of all you gave attention to my heart and spirit. And believe me, those needed tending, too. I have been very scared and exhausted; my family is far away, and this divorce was draining. Then, on top of that, to have this breast cancer! You answered my questions honestly, telling me what you couldn't answer and suggesting others who might be able to help. You didn't run away from my fear. You helped me see I have inner strengths I hadn't realized before.

It's not going to be easy, yet I have more confidence I can do this because of your presence and actions today. So

as a thank you and in hopes that I can bring joy to you, I give this gift to you. I will never forget you.

Inside the soft, rose-colored tissue paper was a little shining crystal star. It caught the light just so, leaving a rainbow in the nurse's hand. Tears came to her eyes as she lifted it out of the box. She then realized she received more than the crystal star. She also received the gift of a little more faith in herself through the gift of Betsy's trust in her. Scientific, spiritual, and practical. Yes. And she was just doing her job.

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