

CHAPTER 1

The Changing Mosaic of Hope

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She was diagnosed with a deadly cancer at age 41. The statistics gave her a chance of living one to three years. She had a degree in math, but she disregarded the statistics. She was hard working, practical, and stoical. She decided to work on living despite cancer.

Cancer is too difficult to manage alone. Everyone needs support and advocacy. As an oncology social worker, my role was to support patients in their visions of hope and to help them refocus their hope when life situations change and hopes are broken.

Case Example

Her name was Donna. She was divorced and had no children, but she had caring family members who lived nearby and who became her daily support. Her treatment began with surgery to remove a tumor from her spine. The surgery was extensive and successful, but she had to learn to walk again. Her niece and nephew became her daily walking partners. Next came daily radiation therapy treatments. Her siblings drove her the 30 miles to the medical center and back time and again.

Her chemotherapy regimen was strenuous and long. Even from the beginning, Donna's hope did not focus on being cured. She realized the odds against that were too great. What she was hoping for was a good remission and time to do some of the things she had dreamed about doing, like traveling to Alaska. She always thought she would have time to travel later in life.

After 24 months of difficult chemotherapy, Donna's cancer did go into remission. When her oncologist gave her the news, he added, "but don't forget you will go out of remission again." He told her he wanted to be realistic with her, that he did not want to give her "false hope."

This created conflict for Donna, and she wanted to understand why her doctor could not be more positive. She had worked so hard to achieve remission, had taken

every treatment, had not complained about the side effects. She had been so hopeful that her life would get back to normal for a while. Just as she achieved remission, she felt he had diminished her hope.

He was the only oncologist in the area, so changing practices was not an option. He had a good reputation, and he did seem to care about her as a person as well as a patient. At one point, we jokingly referred to him as “Dr. Doom.” Donna decided to think of him in those terms and to disregard his negative statements. She decided her hope was bigger than his and that she would help him be more positive.

The remission held, and in the following two years, Donna changed jobs, finding one that was less demanding. Her body had undergone significant trauma, and she needed to marshal her strength. Her hair finally grew back, and she did feel like her life was settling down.

Then something unexpected happened. Donna was diagnosed with an unrelated second cancer. It seemed unfair. She had already been through so much. The cancer had been caught early. She underwent surgery, and the physicians felt that surgery was the only treatment she would need at that time. Once again Donna hoped for an ordinary and manageable life.

Over the next several years, Donna went in and out of remission. Each time, she underwent chemotherapy, complete with hair loss. She had outlived the survival statistics by a large margin. At one point, she had a three-year period where she did not need any chemotherapy treatments at all. Her life seemed fairly settled, and Donna reported that she was happier than before she was diagnosed with cancer. She had made some positive changes in her life, and she felt she was a stronger person for having dealt successfully with adversity.

Slowly, Donna began to have problems with late effects of treatment. She particularly had trouble with her bones. Her ribs broke easily, and she had to limit her physical activity. Some days she had trouble walking or was in pain. It became more difficult to maintain a full work schedule, and finances became a concern. She also had trouble managing her home and property. She decided to sell her house and move back into her mother’s home. The move took place in the fall. That arrangement seemed to work well and was mutually beneficial for both Donna and her mother.

At Christmas, Donna surprised her family by giving each of them—her siblings, their spouses, and children—tickets for a cruise to Alaska the following July. She had used most of the proceeds from the sale of her home to purchase the tickets. This had been a lifetime dream of Donna’s, and she knew her physical condition was deteriorating. She described it as her remaining major goal.

As July approached, there were signs that Donna’s current remission was weakening. Family members expressed concern that the trip might prove too difficult. Donna was not deterred. As she had planned, they all cruised the inner waterway from Vancouver to Alaska. The family spent 10 days together, reliving past memories and creating new ones.

Donna knew that she would be returning to more chemotherapy and that she would once again lose her hair. She knew that she was nearing the end of her illness, that her body could not tolerate much more. Despite that knowledge, Donna made one purchase for herself while in Alaska. It was a beautiful hair barrette made in Russia. Her hope was intact.

Discussion

Hope is a necessary condition for survival. Hope is not static but changes as the situation and circumstances change. Hope is not denial. A well-functioning hope does repress doubts and fears, but true hope is always based in reality.

When most people are diagnosed with cancer, they first hope for a cure. If that is not possible, they usually hope for a long-term remission or for control of the disease process. Donna's cancer was not one that was considered curable. In fact, the projected outcome was poor from her diagnosis onward. She was young and had been healthy up until her cancer occurred. That was in her favor. So was her positive outlook, her determination, and the fact that she never gave up hope.

Donna's physician knew the fatal prognosis and wanted to be cautious. However, by always tempering good news, he made Donna work harder to maintain her hope. Health care professionals generally think of hope in therapeutic terms; they base hope on the possibility of outcome (Groopman, 2004). That does not always serve the patient well.

Patients need and desire accurate and honest information about their diagnosis, their treatment, possible side effects, and prognosis. If presented with compassion and with assurance for continuing support, even bad news can be accepted, and hope can be adjusted as needed.

Hope is complex and individual, and people hope differently (Clark, 2012). Patients base their hopes on a variety of factors. Family hoping styles play a role, as do past personal experiences and coping skills. Donna's family, in general, was practical, positive, and forward looking. She was the first person in the immediate family to develop cancer, and hers was not a common cancer, so they did not have much experience, good or bad, to influence them. They had faced previous family difficulties and were a resilient group. This was an asset for Donna.

Resiliency is defined as a balance between stress and the ability to cope with repeated stress (Greene, 2012). Most families deal with significant problems throughout their history, but a serious, possibly life-shortening illness like cancer—with crisis after crisis—will eventually take its toll.

Cancer changes a family in many ways, some obvious and some subtle, some positive and some negative. When Donna could no longer live in her own home because of financial and physical limitations, she moved into her mother's home. Her mother, who was widowed, welcomed her, but the new arrangement created

additional concerns and stresses for the other siblings who were actually supporting their mother financially.

Family communication became strained, and for a period of time, Donna's family struggled with potential family burnout, a situation that affects families dealing with a prolonged difficult situation or multiple crises (Clark, 2004).

In illness, hopes are not always realized. For Donna, a second cancer was a major setback. In times of broken hope, new hopes must be formulated. Social workers are expert at helping patients reframe their situation, at finding alternatives, and at refocusing hope. One of Donna's ongoing hopes was for her life to return to normal. It was important to help her realize that after a cancer diagnosis and intensive treatment, a new normal must emerge (Leigh & Clark, 2007). With counseling, Donna grasped that concept and created a new normal for herself as she changed jobs and sold her home. Using her diagnosis as an impetus, she made many positive changes over the course of her illness, and she felt her life was better for it. What Donna needed to realize was that her life changes were not always as positive for her family as they were for her.

A life-limiting illness does not necessarily lead to hopelessness. Donna's hope changed as her situation and the facts of her illness changed. She knew she was losing ground physically, and she had a lot of experience in recognizing when a remission was ending. Like most cancer patients, she had become an expert about her own cancer. She had thought about the Alaska trip for a long time and knew she was running out of opportunity. It was the one hope she desperately wanted to realize.

Shortly after she returned from Alaska, Donna and her family were surprised when she was diagnosed with leukemia, a third cancer caused by a decade of chemotherapy. Despite valiant efforts by Donna and her health care team, a remission for the leukemia could not be achieved, and Donna died in February. "Dr. Doom" took care of her until the end, and he thanked Donna for teaching him a great deal about hope.

As a social worker, and before Donna, I had understood the importance of hope and the fact that a hopeless person becomes a helpless person. I had understood the concept of resiliency and the perils of burnout and broken hope. What I learned from Donna, though, was the power of hope. Her life after cancer emphasized the fact that hope is like a kaleidoscope, a changing mosaic. It may need to be refocused time after time, but that does not mean that hopelessness needs to prevail. Donna showed us all that no matter how dire the situation, there is always something to hope for in life.

Discussion Questions

1. *Is it possible to help people reframe their hopes when a situation is dire and the final outcome is known?*
2. *As a social worker, how can you use hope as a clinical construct?*
3. *Can professionals become "hope-lost"?*

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