

**Women's Cancer Resource Center
CEU Program**

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Supporting Materials for Illness as Loss: Grieving the Loss of Health

Excerpt from **Loss, Grief, and Bereavement in the Setting of Cancer**

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Loss and Cancer

All cancer patients and their families experience loss. Loss, grief, and bereavement are a significant part of the cancer experience. Competence in caring for these aspects of the cancer experience should be a high priority for the cancer care team.

Despite the fact that patients routinely face illness-related losses, and despite the frequency with which physicians and other health professionals encounter bereaved patients and families, medical education has historically provided minimal training in addressing issues of loss and grief with patients and families.

Cancer patients face losses from the onset of their illness, starting with the loss of their expectations for their future. Loss results in grief responses; mourning a loss and learning to live life without what is lost are part of creative adaptation. Patients can respond creatively to multiple major losses, but adverse responses to grief can occur. These include anxiety, depression, and associated pathological manifestations.

Family members, caregivers, and members of the cancer care team also experience and respond to losses. This article describes experiences of loss and grief. Methods for screening and assessment, as well as management of uncomplicated and complicated grief, are presented. Finally, approaches to follow-up with bereaved family members are offered.

Loss Terminology

Loss. Loss is the condition of being deprived of something or someone. Loss may be anticipated, real, or perceived; primary or secondary.

Grief. Grief is the experience of a loss. Grief is a personal and normal response to loss. It has emotional, intellectual, spiritual, physical, behavioral, and/or social components.

Mourning. Mourning is the act of grieving -- the outward expression of a loss. Mourning can involve private expressions of grief as well as socially or culturally defined customs such as rituals and traditions.

Bereavement. Bereavement is the state of living with a loss. Grief and bereavement are part of the process of adjusting to a loss.

The Experience of Loss Loss and the Patient

The impact of cancer on patients varies widely, whether the cancer has a good or a poor prognosis, and the losses experienced are multiple and highly individual.

Sense of future. The first loss faced by the cancer patient is often a loss of confidence about the future. Even patients who do not lose hope probably confront this adjustment in some fashion. A cancer diagnosis almost inevitably raises a person's awareness of mortality and places it in a new light. This existential challenge is likely to have ramifications in the psychological and relational domain.

Function. Whether it is the cancer or the treatment that affects function, cancer patients must accommodate a wide range of transient and permanent losses of function (eg, onset of fatigue, inability to perform activities of daily living, loss of normal taste, hearing acuity, or fine cognitive skills). Adaptations to the patient's loss of function often involve family members.

Self-image. Physical losses precipitate a changed self-image. Loss of weight, hair, and/or breast or limb necessitates adjustment of self-image.

Roles. Less tangible, and often very difficult, is the loss of social role that can accompany cancer. Children temporarily or permanently stop attending school. Adults may lose their jobs. A cancer patient may become less functional in a family role as parent, child, or sibling. Losses can also occur in the patient's role in the community, as an active church member, welcoming host, proud gardener, or other group participant.

In place of established roles, patients may take on the "sick" role. In the sick role, the person with cancer may adopt an identity of being dependent. He or she expects and is expected to be cared for by others who tend to needs that he or she cannot fulfill alone.

Society assigns a different role to people who are expected to die soon -- the "dying" role. They are no longer expected to struggle for cure and recovery. They are encouraged to reach a peaceful state with others and offer parting gestures. They are expected to reach some type of conclusion to their life stories or personal legacies. They may be encouraged to make practical arrangements for material gifts and sometimes for their own death-related events, such as funerals. They may be expected to offer designations for successors to the roles they have held in their lifetimes, such as asking a child to "look after mother for me" or a friend to "see to the finances for my child."

Relationships. Along with changing social roles, personal relationships are often in transition. Personal needs change, as do capacities for relating in previously habitual ways. Sexual drive and capacity may change, along with the associated meaning and emotional needs.

Material losses. As personal challenges mount and personal resources are expended in response, material losses can accumulate. Financial losses may be the result of lost income,

medical bills, and practical life changes such as relocating or paying for caregiving.[1] The bathroom, bedroom, and living areas may be transformed by medical equipment that reminds people of sickness or death.

Loss and the Family

Patient losses lead to family losses. Each family member will experience secondary losses as well as having reactions to the patient's losses.

As the patient loses function, the family tends to take up the slack. This may entail gains in roles or relationships, but there are usually losses as well. Family members may have to give up work; modify their expectations of a mother, spouse, or child; make time to perform domestic functions, and so on.

As the patient undergoes changes in functional ability, family members may need to assume new activities such as shopping or bill paying. They may adopt the "caregiver role," and help the patient with toileting or other activities of daily living. The family member may have to develop new skills to perform these new activities. Role transitions may be difficult, and family members may not always have a personality "fit" for adopted roles.

If the patient is terminally ill, as the patient enters the "dying" role, family members, friends, and colleagues begin to take on the role of "successors." They accept the role of guarding the person's personal and material legacies, sometimes completing an unfinished project or recording the dying person's story so that it can be passed down through the generations.

Some personal writing on cancer

“When I got cancer, my shoes got heavy. Partly because of the gravity of the C word, partly because of the grievous thought of not being around for my kids’ lives, partly because of the soul searching that I assume is par for the course when facing one’s mortality, and partly because my feet literally got, and still are a bit, soggy from the chemo. Cancer shook me like I’ve never been shaken and the truth is I don’t know how I’m still standing, except the grace of God, by which I stand- soggy feet and all.”

Shaken But Not Stirred... A Chemo Cocktail by Joules Evans

“It’s probably nothing.” Journal entry September 5, 2006

By early September, I was busy wrapping up the details for Marit’s and my trip to Italy, attempting to learn some essential travel phrases.

Si! Me easy American!

And scheduling a mammoslam.

It had been three years since the atypical ductal hyperplasia was excised from my left breast. I had made it out of the recurrence danger zone of the first two years after excision, and was back to once yearly taffy-pulls, which made my appointment at the Women’s Imaging Center on the morning of September 5th more of an errand than a threat.

With the exception of new digital equipment (let us never take technology for granted), the whole process was routine: I waited until my name was called, donned the paper shrug, told the technician about my history, and assumed the position.

After each angle was captured, I would glance over my shoulder and look at the monitor. While I couldn’t make sense of the images, I could see the technician’s face. It was after she took the last image, when she briefly turned her eyes from the monitor to me, that I saw the slightest shift in her gaze, an almost undetectable beat in an otherwise benign moment in time. I would remember it later but in that instant I didn’t give it a second thought. When she said she needed one more image of the right breast, I mindlessly stepped up to the plates. And when she asked me to wait in the changing room instead of telling me to have a good day, I took a seat, nonchalantly thumbed through a Real Simple magazine, and waited.

And waited.

It wasn't until she came back and told me that "they" wanted an ultrasound of my right breast -- a sound wave induced image that would reveal whether an abnormality was of the fluid or solid variety -- that I considered something might be wrong or at least not totally right.

I lay on my back -- right arm up, hand behind my head -- while the young female sonographer pushed the transducer back and forth across the same bit of breast, looking at the monitor and clicking to take an image.

Looking and clicking.

Looking and clicking.

I knew she saw something I couldn't. It's probably just the same microcalcifications, I told myself. Just a different breast.

I was again left to wait, preoccupied by the hum of a machine that dispersed life-changing images like tarot cards. I plunked down on a stool, rolled over to the sonographer's desk and stared at the pictures on the wall -- the pretty young sonographer, handsome husband, pudgy-cheeked toddler. They looked happy, at ease. She was taking forever to come back, exhibiting pictures of my bosom down the hall. Of all the times to be singled out -- not by a casting director, the hottie on the running trail, or the folks at Megamillions -- but by a buzz-obliterating radiologist.

"Any day now," I mumbled. Mumbling is something I do when I'm alone and waiting for potentially serious bad news. I've mumbled my way through traffic citations, pregnancy tests and unexpected meetings with human resources.

"C'mon, c'mon, c'mon already."

Mumbling is a way of consoling myself, like unbuttoning your pants after eating every last butter-flavored kernel of the large-sized popcorn at the movie theatre. It releases the pressure in my head and keeps hysteria in check. When the sonographer finally did return, I wasn't all that surprised to see the radiologist in tow. Within minutes she was introducing herself, smiling that I-know-something-but-can't-tell-you smile and recommending what would be my third breast biopsy, only this time it would be in my right breast.

A few moments later, I sat in my car in the parking lot and let myself cry. Catching it early is good, I said aloud, not yet knowing what "it" even was. Was I being melodramatic or was I picking up on something more serious, something with a pink ribbon attached? I could have attributed the news to Marit's trepidation about our trip but I didn't. In fact, I had forgotten all about her misgivings. All I could think of was how I was trying

to get all this stuff done before going to Italy. Trying to manage my health. Trying to do the right thing.

It was 2003 all over again. The pink threat of breast cancer had tried to thwart my plans to move from Seattle to Texas then and here it was trying to foil my coveted trip to Italy. And for my 40th birthday, no less! I thought about Mom and how great she was doing since her lumpectomy and radiation -- not a lick of cancer in sight. I thought about my sister who started going in for mammoslams the same year I did but thankfully hadn't experienced anything more than a cyst. They're doing okay, I thought, you're going to be okay too. Whatever it is, you're going to be fine.

“It might not be fine.” -- Journal entry September 11, 2006

Within an hour of leaving the imaging center, I was on the hunt for a breast surgeon to perform a biopsy on my right breast. Not knowing where to look, I called my general practitioner -- the one who wears the flippy girly sandals and colorful crop pants to every exam. You'd think she was going to a garden party not spelunking through my vagina to scrape what feels like a stubborn layer of wallpaper off my cervix. It's always spring when she's around, yet I always feel like a gray lump of clay, sitting heavy and shapeless on the tissue-covered table, telling her the same story I always seem to tell her: no one's visited the dollhouse in months. Just the occasional knock on the door.

She recommended a handful of breast surgeons and said it would be good to consult with one of them from now on anyway, given my history. After narrowing the list to only those in my health insurance network, I read through their bios and settled on one that specialized in breast cancer and promoted survivor fitness. I'd see her in three days.

Email to family, September 5, 2006

After today's mammogram revealed abnormalities, I underwent an ultrasound to determine whether the abnormalities were fluid-filled (cysts) or solid lumps. The radiologist noted two lesions in the right breast: one at ten o'clock (which could be a lymph node) and one at eleven o'clock (more concerned about this). Because the lesions are solid, a biopsy is recommended for both.

My doctor referred me to a breast surgeon who I will consult about a biopsy. (Thankfully, the surgeon is in my health insurance network.)

My doctor was very nice and said, “We're on top of it.”

I wake up and feel groggy on a daily basis. It's part of my charm. But in the days after my ultrasound, I was waking up with an ultra-keen awareness of my surroundings. There was a fraction of time -- about fifteen or twenty minutes -- when I lay there, noting the light through the window; the weight of my comforter; how stretched or buckled my shoulders felt; and the intervals at which the air conditioning would go off and on. I thought about how much it might cost per minute and that I should get up and turn it off.

What if I had cancer? I wondered. What if it was stage four? What would I do if my life were cut short? I thought of all the people I knew who died early: Our family friend's teenage son Matt, three classmates in high school, a twenty-something coworker named Brett, a supervisor named Deborah. Where had they gone? Was I going there too?

The night before the consultation I looked at my breasts in the mirror. I felt the area where the sonographer had spent so much time. There's something in there and I can't feel it. How can that be? I thought about all the jokes I made over the years about their small size and cone shape. A way bustier Marit and I often laughed about how when she spills food it lands on her shirt. When I spill food it lands in my lap. I had been critical about them being too far apart, too pointy, too flat when I lie down. But that night, I thought they looked pretty damn good and I didn't want to lose them.

I Don't Wanna Be Pink by Dena Taylor

As if he'd done this a thousand times, the doctor firmly explained my test results. He said they ran three separate blood counts on me and each one indicated my white blood cell count had become worse. In his banter of medical terminology to describe what was wrong I heard one big word that hurled me into complete disarray for a few minutes. Stunned, upon realizing that I *had it*, absolute terror poured into me. *Leukemia* slipped

from between his lips, causing everything else he said to dissolve into nothingness. I felt absolutely helpless, sitting in bed; wearing a blue hospital gown. Nothing came out of my mouth and my face robotically fell into neutral position. I responded by returning a blank expression while attempting to digest my unexpected and forbidding fate. *Yes, leukemia was a big word for an even bigger disease.*

My initial reaction dwindled and I don't know what I felt other than a profound numbness upon hearing I had *late stage three, leukemia*. Now that I had cancer, I didn't know what to expect. Can they treat it? Am I going to get worse? Is this terminal? What happens now? I had a plethora of questions, but I wasn't sure I was ready to ask, so I nodded and remained quiet. Once the oncologist left the room I took a deep breath before trying to make sense of the unsettling report.

Bad to the Bone, the story of David Tucarro