

# Chapter Eleven

## Final Gifts: Disease Progression, Hard Choices, Last Days

This chapter was hard to write. It will probably be hard for you to read, too, since it discusses what happens during the final stages of metastatic breast cancer, when the available treatments are no longer effective, and the disease, beyond controlling, overtakes the body and causes death.

Like most women who have had breast cancer, when someone I know and care about dies from the disease, I can't help feeling a cold shiver of dread along with the sense of grief. Losing someone I am close to brings my own death closer, making me wonder when and how it will come. Yet, facing death and dying head on can have its benefits, too, as I hope to show in this chapter.

The early sections of the chapter deal with the confusing and difficult end-of-life decisions patients and physicians must often make, and with the problems most of us have in confronting the dying process, making treatment choices, and allowing ourselves to talk openly about our own fears and wishes.

Gerry Wirth, whose wife, Cindy, died in February 1996, evoked the process as he experienced it: "This disease started like a mist, deepened into fog and ended like a tornado." At the end of this chapter, Gerry and five other husbands recount the final stages of their wives' illness and describe their deaths.

### **No one is talking about what everyone knows**

Drawing up a will is hard enough, not to mention drafting an advance directive and health care proxy, where you have to make your wishes about life-sustaining interventions clear and appoint someone you trust to make medical decisions for you when you are no longer able to. Why, you may well ask, should this book even include a chapter on dying? Isn't the real point to focus on *living* with metastatic breast cancer as long and as well as you can? An open discussion about dying only seems to bring the reality of death that much

closer, and to undermine the positive attitude and fighting spirit so many feel is important. Often, dying cancer patients and their families feel that by avoiding this topic, they will somehow avoid burdening one another further, and causing even more pain. And so they never talk directly about death and dying.

Yet the process of talking about dying, and planning for these contingencies, can also bring a sense of relief and connection, whether it is many months or even years beforehand, or when the person is in the final stages of illness. It's not as if these thoughts can be entirely banished from your mind, even if you would wish it. An awareness of mortality is a fundamental part of the human condition, and never more so than when you face death imminently. Avoiding these thoughts and discussions often drains away necessary energies, limits intimacy and increases feelings of isolation and depression.

Psychologist Froma Walsh, President of the American Family Therapy Association, is concerned about the impact on families when these feelings aren't communicated:

*We have social expectations that inhibit us from saying the "D" word, and we keep thinking, "I shouldn't say, 'are you dying' or 'you may die soon.'" Perhaps it's partly the fear that if I say it out loud he may think I want it to happen, or if I say it out loud maybe it'll happen sooner. It's kind of a superstitious belief.*

*To say to someone, "You're dying, aren't you? or "Are you dying?" or "Do you think you're dying?" may help that person feel more comfortable. Often there's tremendous relief when the person who's dying can now say it out loud. What he may say is, "Yes, but I didn't know if you realized it," or "I didn't want you to feel worse by talking about it." Everybody avoids talking about it because they're afraid they're all going to break down in tremendous grief or it will be too painful for others. If there were a single message, it's for people to take that risk to talk about the unspeakable together.<sup>1</sup>*

Dr. Fred Schwartz, Medical Director of the Visiting Nurse Service of New York Hospice Care, reports that his hospice team is sometimes asked by family members to withhold the severity of the prognosis from a patient, which they will agree to do, unless the patient asks directly. There's a price to be paid, however.

*When we go into the situation, there's often a sort of heaviness, because no one is talking about what everyone knows. Patients almost always know that they are dying. They may not want to talk about it, or they may not want to talk about it with family. But they almost always know, because they can feel the energy slipping from their bodies. They know they're not getting better. And they are protecting the family, often, by not talking about it. And the family, likewise, seeing the patient deteriorating, will not talk about it. So there's a sort of conspiracy that goes on. It really blocks the most heartfelt communication between people. Very often, I will come and during the visit with the patient, when the family's gathered around, the patient will say, "I know I'm dying. How much time do you think I have?" Or "Will it be painful?" And this is the first time this will have come up. It's often a real revelation to them, and breaks through a lot of barriers.*

Another isolating factor often enters into the final weeks and months of a person's life. Very ill people often withdraw into their "inner circles," as sociologist Kathy Charmaz says.

*Immersion in illness shrinks social worlds. It forces people to pull into their inner circle while pulling away from others. They must try to protect themselves and to keep some control over their lives. They have little strength for anything beyond illness.... Pulling in permits ill people and their caregivers to tighten the boundaries of their lives, to reorder their priorities, and to struggle with the exigencies of illness.<sup>2</sup>*

Necessary though this may be, Charmaz points out, pulling in "sets an empty stage for future social isolation."

As her illness visibly progressed, PJ Hagler felt the withdrawal of friends and members of her church keenly and wondered what to do about it.

*I have tried to let people know that should the time come, I'm okay with it. I still want to be part of life though. I wonder why the need to pull away is there other than maybe no one feels comfortable discussing this topic. We are all given a death sentence when we are told we have cancer unless we are blessed with remission. So many of us with mets have to live with this idea of dying, yet we find it difficult to bring it up, even with each other. Do we try to avoid reality?*

Bob Stafford agreed with PJ:

*I know the fear people go through and the hope they so desire to have. And sometimes we have lied to them through silence. One of the freeing aspects, though, is the acknowledgment of our mortality. Then we really can begin to enjoy life.*

Nancy Gilpatrick also sensed the need for openness in discussing this difficult topic. "Let us please talk about dying," she wrote back. "It will help us to live."

People throughout history have seen for themselves the seeming paradox Nancy alludes to: that confronting death leads to increased aliveness, and that avoidance only begets a diminished sense of self. The psychologist Carl Gustav Jung believed that "We do not become enlightened by imagining figures of light, but by making the darkness conscious."

Dr. Irvin Yalom, an existential psychiatrist who has worked for many years with terminally ill cancer patients at Stanford University, wrote:

*...death is the condition that makes it possible for us to live life in an authentic fashion....A denial of death at any level is a denial of one's basic nature and begets an increasingly pervasive restriction of awareness and experience. The integration of the idea of death saves us; rather than sentence us to existences of terror or bleak pessimism, it acts as a catalyst to plunge us into more authentic life modes, and it enhances our pleasure in the living of life.<sup>3</sup>*

It is all very well to speak in vague terms about confronting mortality, but for the metastatic cancer patient whose illness is far advanced, these lofty issues take on real and immediate proportions, when patients have to confront decisions about ending active treatment and entering palliative care.

## **Isn't there something else we can try?**

“When I think about this time, I have conflicting feelings,” Gerry Wirth said, recalling the period between Cindy’s high-dose chemotherapy treatment and the discovery of further metastases. “I remember it as a time of great hope, great anxiety, great joy and great disappointment. I also remember it as when I began to feel it wasn't a question of whether, only a question of when.”

As we have seen, living with metastatic breast cancer frequently involves trying one treatment after another over an extended period of time, often a number of years. Each time a hormonal treatment or chemotherapy drug or combination of drugs is used, the cells of the cancer work hard to survive by mutating to become resistant to that and related treatments. In the later stages of the disease, metastatic sites also tend to become larger, and more widely spread, invading other organs, causing pain and interfering with normal functioning more and more.

At the same time as treatments are becoming less effective, their toxicity is likely to be greater as the patient becomes sicker. Since it’s impossible to know for certain if a treatment will work until it is tried, many oncologists and patients are inclined to try one drug after another, until it is obvious that no other treatments make sense, the person is too debilitated to withstand further treatment and the disease is finally beyond controlling. This agonizing process often takes everyone involved through fluctuating cycles of hope and despair.

On Thanksgiving of 1996, after six years with metastatic disease, PJ Hagler was in despair, as one treatment after another had failed to reduce the size of the metastases in her liver:

*Last week we were told I don't have much longer to live and that this will most likely be my last Christmas. I'm still on 5-FU by pump, but the oncologist said I will probably only tolerate it for about one more week. We are asking him to try compassionate treatment with Her2-Neu or anything else he can think of. I'm still well enough to fight this thing. I'm not ready to die.*

*Mike and I talked about it this weekend and I still have fight left in me if they would just let me try....I know there is something out there that would help me live longer....I'm so depressed right now because it feels like I should be able to do something to live if I'm willing to go through the pain of the treatments.*

*I'm only 46 and I want to live. Is there something so wrong with that? My friends were talking about retirement and I want to go to the place we always dreamed about in the mountains to retire.*

By New Year's day, after a hospital stay and an adjustment of medications, PJ was more philosophical as she examined the preceding year:

*I have been on one type of chemo or another since last February. Not much has helped this year but I'm still here. So while I say the chemo hasn't worked, it has bought me time. My oncologist and I will use whatever we can find. I have a great deal of faith in him and also in God. I know I will die when I'm supposed to, and not a day early. So much has changed since 1983 when I first discovered my breast lump. The meds I've taken just this year didn't even exist then. God has given me almost fourteen years that I didn't expect.*

But later that month, PJ was in the hospital again with pleurisy, pain and difficulty breathing caused by the pressure of her swollen liver.

*I'm in rotten shape right now, but I have been in rotten shape before. I don't know how to quit. I have heard all this praise and positive thoughts about how I am handling the latest bad reports. I don't know any other way to handle them.*

One month later, PJ finally had good news:

*Dr. Nick was so excited today that he called me at home. Last Thursday I saw him and he took the tumor marker blood test. I had the last one in December and it was in the 80's, which is the lowest I've had in six years. Well, he called today to say he wanted to give me the first real good news he has been able to give me in forever. My markers are 10!!*

*I have to give God the credit for how much better I am feeling. My oncologist even said, "I am good, but I'm not that good." But God is good enough to make you well. He does good work. He answers prayers.*

A few days after that, still filled with gratitude for this latest reprieve, PJ reflected in a letter to another woman who had been feeling desperate:

*I would love to be whole and well again for one day in my life. But this is not going to happen. We all know that up front. But we can live each day to the fullest and if it's a bad day we just get through it until the next good day. We all have ups and downs, believe me. People tell me how courageous and strong I am. Well, I love my life and I love Mike so much I can't even think about our life together ending. And I have faith that God is using me and my breast cancer to help others realize it doesn't have to be a death sentence....But the bottom line is I don't know how else to live. I can't imagine giving up and not doing treatments or whatever it takes to keep living. I don't want you to think I'm saying don't get discouraged or down or sad. That's impossible. It happens. But please keep fighting. Life is so worth living.*

After a summer of nausea, pain and lowering blood counts, Kathy Stone wrote on Thanksgiving 1996 that she had been feeling somewhat better.

*Seems my red count along with platelets and other "things" that are looked at in blood tests have been steadily declining for the past five weeks now (I get a blood test every week, a fasting panel every three weeks). My white count on my last test*

*dropped in half. I haven't been on chemo since the beginning of July/end of June...can't quite remember, I was so sick when we decided that chemo was no longer the route to go. Since I've had all the "big guns," as they say, and the mets are continuing to steadily grow, the doctors and myself felt that we would save whatever there is left to save in the way of chemo for when we need to really slow this sucker down again. Anyway, the doctor feels that the continuing dropping of the red counts is due to the cancer now being in the bone marrow. The drop in the white count is still unexplained unless they just caught me on a curve. I did have a sinus infection that day.*

*As for how I feel, I haven't felt so good in a long, long time. This past spring and summer were pure hell with all the nausea and unknown illness I went through....The bones are degenerating and I had lots of pain ...but now it seems that the pain medication is working. I have a good combo going of Dilaudid and MS Contin and Toradol, along with the steroids that help with pain also. Talk about appetite....Two months ago I didn't want to hear the word food...today, I can't get enough of it!*

*Well, that's where I'm at...feeling good but knowing that this crazy, awful stuff is continuing to grow in me. I have several soft-tissue tumors in and around my clavicle, neck and left shoulder area, with some cutting blood supply and giving pain.*

Three months later, Kathy's disease had progressed still further:

*I just got home from the oncologist's office. CT scan of chest wasn't too bad, but wasn't good either...showed up new mets and more mets in old areas. Still can't find the reason for so much crippling pain in left shoulder, chest area, rib area. Doctors think it is referred pain from my sternum and spine because they are so badly full of tumors. It feels like someone broke my ribs and then sat down on them. I was upset and mad that nothing concrete was said in the report of that specific area. Anyway...due to all the new mets in the bone scan and CT scan they are going to put me back on chemo...trying to help pain and maybe slow mets down some, but I think it is mostly for the pain so I keep doubting if I should be doing it....The pain is bad, so maybe this chemo will help. Who knows?*

*I am so confused this afternoon and all I want to do is cry, but am too tired to even do that for too long at a time.... I'm so sick and tired of it all....When does it stop, or does it? I guess we just keep on fighting until there is no more fight left in us.*

The next day, Kathy was reconciled to the thought of more treatments, relieved that her husband, Chuck, would go with her to the doctor's office. Through the support of family and friends, she had recaptured some of her usual resilience:

*I do dread the new chemo, I'm tired of being tired, but ya gotta do what ya gotta do...right? And I never want to give in or up as long as they think there is a bit of hope to slow this sucker down. Life is too precious.*

*If we can just stay sick long enough, a cure will be found and we will be able to get completely well and whole again with it. I'm going try to stay sick for as long as it takes...and in the meantime, no telling where you will find me because I don't plan on staying put in the house or in the bed when not absolutely necessary. I plan on living and enjoying everything I can....My motto is you can hurt and be sick outside your home as well as inside, so why not go out and have fun if it's manageable at all. Anyway, as I've said before...it makes it that much harder on "ole man death" ...he just might get tired of looking for me and give up!*

When asked how they might come to a decision about when it wouldn't make sense to continue treatment, most of the people I interviewed chose not to respond, saying that they felt they were far away from that decision point and found it too depressing to think about. Those who did talked about how difficult this decision would be for them. How would they know when to stop? they wondered. If there was any chance at all a treatment will work, how could they say no to it?

## **End-of-life dilemmas**

However personal they may be, these decisions also touch on issues of medical history and ethics, as well as public health policy. Just as it helps to grapple with your feelings if you know they are shared by others, it may also help to frame individual experience in the larger medical and social context. Understanding the forces at work in our society against confronting the reality of death explains much of the withdrawal and avoidance many metastatic breast cancer patients feel coming from their health care providers. Daniel Callahan, medical ethicist and president of the Hastings Institute, focuses the question:

*Is death to be accepted as a part of life, or fought to the end? Most doctors, and most Americans, are just not certain what the answer to that question is—and it shows in the way patients are treated at the end of their lives, and sometimes in the way they (or their families) are treated.<sup>4</sup>*

Part of the problem is that death, far from being understood by the medical establishment as a final outcome of many diseases, is usually defined as outside the proper scientific scope of medicine. *Cecil Textbook of Medicine*, the recently revised and classic primary guide for physicians, devotes only 25 of its 2,300 pages to death, and only five pages to pain.

*For a book filled with accounts of lethal disease and ways to treat them, there is a strikingly scant discussion—three pages only of treatment for those in the terminal phase of disease. It tells what to do to hold off death, but not what is to be done when that is not possible. That omission is a stark example of the way death is kept beyond the borders of medicine, an unwelcome, unwanted, unexpected, and ultimately accidental intruder.<sup>5</sup>*

Ellen Scheiner has the uncommon perspective of being both a high-risk breast cancer patient and a doctor with a lifelong interest and experience in medical ethics. Ellen gave the first “death and dying” lecture to the experimental chemotherapy unit at Memorial Sloane-Kettering Cancer Center in 1968. “No one died there,” she says wryly.

As a physician who always prided herself on her compassion, Ellen thought she'd understood before her own intensive chemotherapy what patients with advanced cancer felt. But her own experience with the "dissolution of self" that came with her chemotherapy was a revelation, and has caused her to reflect on her own wishes, should she have a recurrence.

*I'm a living example of a doctor who didn't want to keep patients alive beyond their time, who still didn't understand what it was like. At this time, at age 63, if I got a recurrence, I would take simple treatment. That's all that I would do. When I was first diagnosed I wanted a real crack at living, I wanted to give myself the best possible chance. I think I've been given this life and I am responsible for maintaining it. But I need not abuse it by overtreating myself.*

*The simple statement, "You know you have a choice of doing absolutely nothing, and there's nothing wrong with that. You can live in a comfortable way, or there might be lesser treatment, and pain medication." I think these simple sentences are not said, often. If they were, people might say, "Oh, I don't want any more treatment, then. I'd rather have my grandchildren in my lap."*

*I've already told Vicky [her oncologist] that if I get a recurrence, I don't want Taxol. It made me too sick. I told her at the beginning: "I don't want to be kept alive heroically. I'm going to take this, and I'm going to fight like hell to get through this treatment." I've told the people who have my health care proxy what I want. I know, because I am a doctor, that people don't need to have treatment. They need to hear it from somebody who will say, "You don't have to do this."*

Ellen has thought further about the dying process she might seek for herself.

*I know that I might have painful metastatic cancer, for which I can foresee palliative treatment, and that I might need to enter a hospice for pain management until my death. Although sedated, I could be still surrounded by loved ones and enjoy a touch, a strand of Bach, the way light streams through a window. I would not seek death.*

A "good death" is not always possible, as Ellen knows. There are some circumstances under which life would no longer be desirable for her.

*The worst scenario for me is that I could no longer think clearly or enjoy anything much because my thinking apparatus itself was affected. Possible reasons include dementia or an encephalopathy, which is difficulty in perception because of a chemical derangement or brain metastases. In this context I would prefer not to live. As a physician I know well how to commit suicide.*

*However, I might not have the mental capacity to act. I would not presume to ask a friend or colleague to assist me (assisted suicide), if indeed I could recognize my altered mental state, because that person would be guilty of murder under our present laws. I am familiar with cases in which assisted suicide has been attempted and the person has not died. My wishes are known in advance, and someone might seek help for me if I lost awareness. This, for me, makes a strong case for euthanasia, or a legally approved way of having competent people*

*confirm the patient's mind state, and of carrying out the patient's wish to die . Laws would need to be amplified and, in all probability, physicians would need to administer the lethal agents. I hope that these laws are enacted before I need them.*

As a physician willing and able to discuss death and dying openly, even when it comes to her own predicament, Ellen represents a minority in her profession. Nowhere is the avoidance of end-of-life discussions on the part of doctors and patients more evident and more tragic than in the hospital care of the dying. The findings of a broad study of the care of critically ill patients, entitled SUPPORT, involving nearly 10,000 hospitalized patients in the advanced stages of cancer and other terminal conditions, in five leading medical centers, were published in the *Journal of the American Medical Association* in November 1995.<sup>6</sup>

“Many Americans today fear they will lose control over their lives if they become critically ill, and their dying will be prolonged and impersonal,” the study authors state in the introduction, echoing the fears most metastatic breast cancer patients express. These concerns have given rise, the study authors go on to say, to a visible right-to-die movement and widespread concern about the “economic and human cost” of end-of-life treatment. They have also led to efforts by consumer and professional organizations to promote health proxies and advance directives, and to search for ways to facilitate better doctor-patient communication about end-of-life decision making.

Prior studies had indicated that “communication is often absent or occurs only during a crisis. Physicians today perceive death as a failure...and they provide more extensive treatment to seriously ill patients than they would choose for themselves.” Consequently, this study was designed to look at communications between medical professionals and patients near the end of life, a time when doctors don’t clearly convey patients’ chances for survival, and patients and families don’t discuss their wishes soon, or often, enough.

In fact, the outcomes of the first phase of the SUPPORT study, which involved 4,301 patients, led to some shocking findings:

- *The SUPPORT patients were all seriously ill, and their dying proved to be predictable, yet discussions and decisions substantially in advance of death were uncommon.*
- *Communication between physicians and patients was poor: only 41% of patients in the study reported talking to their physicians about prognosis or about cardiopulmonary resuscitation (CPR).*
- *Physicians misunderstood patients’ preferences regarding CPR in 80% of cases.*
- *Furthermore, physicians did not implement patients refusals of interventions. When patients wanted CPR withheld, a do-not-resuscitate (DNR) order was never written in about 50% of cases. Nearly half of the DNR orders were written in the last 2 days of life.*

- *The final hospitalization for half of patients included more than 8 days in generally undesirable states: in an ICU, receiving mechanical ventilation, or comatose.*
- *Families reported that half of the patients who were able to communicate in their last few days spent most of the time in moderate to severe pain.*

To rectify these conditions, over the two years of the intervention phase of the SUPPORT study, specially trained nurses facilitated communication about risks, outcomes and choices with 4,800 patients, their physicians and families, in an effort to ensure that patients' wishes were followed and decision-making was informed and collaborative. But this intervention didn't make any difference: "Improved information, enhanced conversation, and an explicit effort to encourage use of outcomes and preferences in decision-making were completely ineffectual."

Dr. Joanne Lynn, director of the Center to Improve Care of the Dying at George Washington University, and one of the project coordinators, interpreted the disappointing results:

*The reasons for this are ingrained in our society. Physicians are taught to save lives, that death is a failure. Patients and families have come to expect miracles in every case. It's easier for everyone—professionals and patients alike --to follow the usual path of aggressive treatment, even when it's clear that it is leading nowhere. No one wants to give up too soon. That's one reason why everyone is so reluctant to discuss dying.*

*Suffering while dying must become a bad outcome in the health care system. Everyone has a vision for living. Our society also needs to create a vision for living well while dying.<sup>7</sup>*

Daniel Callahan, commenting on the failures of the SUPPORT study interventions, takes this back to a personal level:

*It has too often been presumed that people know what they really want, that they can know in advance what they want, and that clear choices—yes/no, on/off—will present themselves. Those seem to be wrong, excessively rationalistic presumptions. The only real surprise is that those who should be more perceptive about human nature have believed that what patients say they want is exactly what they do want. I wish I knew myself that well—and especially knew how I will react to the (by definition) once-in-a-lifetime circumstance of my dying. Where am I supposed to get that kind of knowledge about myself, much less certainty about what I think I know? Where is anyone to get it?<sup>8</sup>*

When they are still healthy, people may be quick to say they would discontinue treatment as soon as recovery seems unlikely and significant loss of quality of life appears imminent. But in the moment of crisis, many—perhaps most of us—will accept treatment as long as it is offered. Panic and the physiological instinct to survive are strong influences, especially when these choices haven't been thought through in advance. These scenarios are all too familiar. An elderly friend of mine, dying of lung cancer, was taken to the hospital in respiratory crisis. Panic-stricken, she agreed to a ventilator, something

she'd expressly rejected in her advance directive. "Terrible mistake," she was able to scrawl in a note to her husband after she was stabilized, and asked that he arrange for her to be sedated and withdrawn from the ventilator, so that she could die in peace.

In February of 1996, eleven years after her liver metastases had first been diagnosed, Jenilu Schoolman wrote her friends that her oncologist had told her "it is all over but the shouting."

*My liver is pretty well shot with tumors that are out of control. My back is filled with metastases to the point of bones being about to shatter from the weight of my own body. In short, things look very grim. I will spare you all the gory details of the past week because they haven't been pretty and I don't want to hurt you with my pain. Suffice it to say, I began chemotherapy on Tuesday with three drugs that are new to me. My oncologist said plainly he doesn't hold out much hope that they will do any good and he wouldn't blame me if I decided not to go on with treatment. But on the other hand he knows me, and he knows I'll try anything.*

*The radiation oncologist feels she can do a good deal for my pain, but she is very worried that so much of the bony part of my lower back is involved that, as the radiation wipes out the affected tissue, there won't be enough bone to support my body and whatever is left will simply shatter. So I am wearing one of those belts that carpenters and men who work lifting wear, hoping that will provide enough support to get me through the time when I have little bone. We have also added more morphine to my regime, which seems like an excellent idea.*

*Other than that, I am still working. The schedule for radiation is stable. It's the same time every day so I can actually plan! I am also holding an open house for all my patients, past and present, so I can say good-bye to them and let them say good-bye to me. This is not fun....*

*However, I must admit that in spite of all the Cassandras in my life, I am still optimistic. Or crazy! I told my oncologist that if I could find a window in this nasty space, I'd climb out and run away. He looked at me quizzically. I explained that since childhood I have had a problem climbing out windows and running away; playing hooky. When I worked at Ellis Hospital this reached monumental proportions because I had a basement office. Especially in spring, I'd lock my door, climb out the window and I was gone! Unfortunately I never told the secretary I was leaving and I know I caused havoc a number of times but...that's the wild woman in me that just can't be tamed. Well, I'm about to use that same wild strength to find another window and climb out of this mess. My doctor laughed and said he was sure that if it were possible, I'd do it. Remember I did it eleven years ago, so why not now?*

Like many others, Jenilu coped by entertaining a dual possibility: making realistic preparations for her death, while at the same time still hoping that further treatment might give her more time. When Jenilu died two weeks later, at home under hospice care, my first thought was that she had been right about climbing out that window.

## Hope and treatment choices

But what about hope? Doesn't giving up treatment mean giving up hope? Yale surgeon and professor Sherwin Nuland writes cogently about how hope can become transformed during the course of terminal illness.

*Hope lies not only in an expectation of cure or even of the remission of present distress. For dying patients, the hope of cure will always be shown to be ultimately false, and even the hope of relief too often turns to ashes. When my time comes, I will seek hope in the knowledge that insofar as possible I will not be allowed to suffer or be subjected to needless attempts to maintain life; I will seek it in the certainty that I will not be abandoned to die alone; I am seeking it now, in the way I try to live my life, so that those who value what I am will have profited by my time on earth and be left with comforting recollections of what we have meant to one another.*

*There are those who will find hope in faith and their belief in an afterlife; some will look forward to the moment a milestone is reached or a deed is accomplished; there are even some whose hope is centered on maintaining the kind of control that will permit them the means to decide the moment of their death...Whatever form it may take, each of us must find hope in his or her own way.<sup>9</sup>*

Most of the people I interviewed expressed a need to preserve hope through continuing treatment. But often, as time went on, and the disease progressed, their hope found other measures, more modest perhaps, but no less meaningful: for more time with family, to accomplish life ambitions, or to be present at crucial events. "I would argue that of the many kinds of hope a doctor can help his patient find at the very end of life," Nuland writes, "the one that encompasses all the rest is the belief that one final success may yet be achieved whose promise vanquishes the immediacy of suffering and sorrow."<sup>10</sup>

As the SUPPORT study suggests, many, if not most, people are willing to gamble against heavy odds and debilitating side effects for a slight chance at more of this precious commodity called time. This disturbs Nuland, who writes of the seductive lure of high-tech medicine for his late-stage cancer patients, few of whom, he reveals, were willing to say "no more" to treatment.

*Almost everyone seems to want to take a chance with the slim statistics that oncologists give to patients with advanced disease. Usually, they suffer for it, they lay waste their last months for it, and they die anyway, having magnified the burdens they and those who love them must carry in the final moments. Though everyone may yearn for a tranquil death, the basic instinct to stay alive is a far more powerful force.<sup>11</sup>*

A further reason for this may lie in our capacity to accept death in the abstract, that it must come to each of us, but not in the particular, that our dying or that of someone we love may be *here and now*...and that it may be time to change one's focus from fighting the cancer to thinking about letting go. Easy to say, but much more difficult to do. The

power of hindsight being what it is, Callahan believes that the way in which these decisions are often made is a complex process:

*The answer often comes down to a series of subtle, small, incremental steps, none of which actually thwarted patient or family wishes in any obvious fashion, and each of which was based on some hopeful medical possibility, with both the hope and the possibility stimulating each other to the point of folly.*

*More generally, we fail to realize how profoundly ambivalent most of us are about accepting death, not just because of the threat of death itself, but because we are heirs of the same tradition of technological optimism that has dominated modern medicine. Even if we say we can accept death, we believe in our hearts that the sting of death can be medically delayed, that fatalism is itself a source of fatality, that death is a kind of human artifact. No less than physicians have we laypeople come to believe that part of the success of modern medicine stems from a commitment to a zealous use of technology, a zeal no place better expressed than at the margins and against the odds.*

*We believe as a general value that one ought, with spirit, to fight death. We may with all sincerity mean it when we say we do not want clearly useless or futile treatment. But that is not of much help when clinical uncertainty or psychological ambivalence are present; then we may waver, unsure of ourselves.<sup>12</sup>*

Though far from this stage in her own illness, Sharon Multhauf has stood by as many friends have faced these choices:

*It would be awfully hard for me to say "no more treatment" as long as there was reason to hope that treatment could buy me more time with my family and friends. But my hope is that such time would have some measure of quality to it. In other words, I am willing to be in a wheelchair, I am willing to be bedridden, as long as I am not experiencing constant pain and nausea, which would make it hard to enjoy being with my loved ones. And if I'm so spaced out from narcotics that I can't communicate, what good is the time I have? I know that there is a lot that can be done to control pain and nausea, especially when addiction and long-term effects are not constraints. Therefore, I expect that I would want to try one more therapy, and one more, and one more, to squeeze some more time out of this life of mine, even if I was fully aware that none of these would cure me. The time when I would say "enough is enough" would probably be when the treatment's side effects could not be controlled enough to let me enjoy my loved ones.*

*I will rely on my doctors to tell me what they know, and on Lloyd to offer his support, wisdom and love, but ultimately, the decision is going to be mine. I'm the one living in this body, and if anyone on this earth is going to decide it's time to leave, I think it should be me.*

For Nancy Gilpatrick, it is the sickening memory of how she had felt after her high-dose chemotherapy that leads her to feel she might stop treatment at a certain point.

*I won't do chemotherapy until the end of my life. I want to enjoy my life until there isn't any life left in me. Those two sentences convey a lot of information in few*

*words. Behind those words are lots of sleepless nights, conversations with Terry, and reading the words of women on the breast cancer list. It's also a promise I made myself after the high-dose chemo: no more chemo. I was so sick and weakened I didn't want to do it again. I may do more chemo; its just that there will be an end.*

*Since I've been told I will in all likelihood die from the breast cancer or mets, as a relatively young woman I want to have a good quality of life, while trying to find a balance in quantity. I don't want to be bedridden any more than is absolutely necessary. My cancer has not responded well to chemo and so I'm not interested in running through the different meds to find the one drug that will work. I'd be despairing and disappointed while having to recover from the side effects of chemo.*

Since facing death is painful for all of us, it's probably human nature that we instinctively turn away and try to ignore its reality when we can. A large part of the courage metastatic breast cancer patients ultimately find in themselves relates to this confrontation. Dr. Irvin Yalom quotes psychologist Otto Rank describing a neurotic as one "who refuses the loan (life) in order to avoid the payment of the debt (death)."

Contemplating one's own death and dying creates anxiety, which Yalom calls "the price you pay for being fully human."<sup>13</sup> Caren Buffum, like the others interviewed for this book, struggled with paying that price.

*What is probably most prevalent on people's minds, the question they would really like to ask but rarely do so, is how do I deal with the idea of dying from this disease. How am I so calmly "facing death"?*

*I first dealt with this issue in a clear and conscious way when I thought about doing a "living will." I was asked over and over again at each admission at the NIH for my treatment back in 1992-93 if I had prepared a living will or advance directive. Each time, I told myself I probably should make one out, but each time I felt like that would be admitting that I was going to die soon and, in some weird way, I might even hasten the event's arrival. But I thought about all the people who have died totally unexpectedly. Of course the Karen Ann Quinlan case immediately came to mind because of all the media coverage. But hers was a classic case of the confusion caused by an untimely situation that no one was prepared for. It occurred to me that everyone had to deal with the issue of dying, if for no other reason than to realize that it was a reality of life and there were things we each need to do that we may not have advance notice on.*

*So I finally sat down and put my living will together, almost with a smug satisfaction that I had done a responsible thing that most other people simply put off until it's too late. I could deal with the reality of death as not so much the result of my having cancer but, rather, the result of my having life. It gave me a new way to look at dying—not as an imminent event but, rather, as an unavoidable one.*

## The problem with doctors

Doctors are no more immune to a fear of death than the rest of us, it seems—especially when they see death not as a natural and inevitable outcome of disease, but as a personal defeat or failure. Research suggests that some doctors may even be drawn to medicine by unusually strong fears of death, even a need to conquer it. “It’s frightening for a lot of physicians to deal with dying patients,” writes Yalom. “Physicians find lots of ways to get away from these patients quickly.”<sup>14</sup> Because this abandonment can be devastating, and a close and trusting relationship with an oncologist is so crucial throughout the course of the disease, many of the people in this book have made a point of discussing these issues freely with their doctors far in advance, making sure that their wishes were explicit and would be honored, and trying to gauge their doctors’ commitment to them.

Anyone facing end-of-life decisions concerning medical treatment would do well to heed Sherwin Nuland’s cautions about medical arrogance and abandonment:

*In an attempt to maintain control, a doctor, usually without being aware of it, convinces himself that he knows better than the patient what course is proper. He dispenses only as much information as he deems fit, thereby influencing a patient’s decision-making in ways he does not recognize as self-serving....The inability to face the consequences presented by loss of control often leads a physician to walk away from situations in which his power no longer exists, and this must certainly be an ingredient in the abrogation of responsibility that so often takes place at the end of a patient’s life.*<sup>15</sup>

The source is more than a matter of individual ego, Nuland believes. These attitudes are the spoils of a century that has indulged in the “conceit” of the mastery of science and medicine over the inevitability of nature.

*Every time a patient dies, his doctor is reminded that his own and mankind’s control over natural forces is limited and will always remain so....The greater humility that should have come with greater knowledge is instead replaced by medical hubris: since we can do so much, there is no limit to what should be attempted—today, and for this patient!*

No more poignant or instructive example of a doctor’s vulnerability exists than Nuland’s recounting of his brother’s death, in which he admits how and why he withheld the truth that his brother was dying from him, regressing, as he acknowledges, to “the misconceived paternalistic dictum of the professors who taught me a generation ago: ‘Share your optimisms and keep your pessimisms to yourself.’”

*No one who has treated cancer patients will ever discount the power of the subconscious mechanism we call denial, which is both friend and enemy of a person seriously ill. Denial protects while it hinders, and softens for a moment what it eventually makes more difficult.*<sup>16</sup>

In his essay *Intoxicated by My Illness*, the critic Anatole Broyard, dying of prostate cancer, issued this challenge to physicians:

*Not every patient can be saved, but his illness may be eased by the way the doctor responds to him—and in responding to him, the doctor may save himself. But first he must become a student again; he has to dissect the cadaver of his professional persona; he must see that his silence and neutrality are unnatural. It may be necessary to give up some of his authority in exchange for his humanity, but as the old family doctors knew, this is not a bad bargain. In learning to talk to his patients, the doctor may talk himself back into loving his work. He has little to lose and everything to gain by letting the sick man enter his heart. If he does, they can share, as few others can, the wonder, terror, and exaltation of being on the edge of being, between the natural and the supernatural.<sup>17</sup>*

Bob Stafford relies on his doctors to be candid with him about the time when treatment will no longer make sense:

*I want my doctors to be deadly honest with me. I'll find the hope, I already have the hope that I'll need. But I want them to tell it like it is, even if they are wrong. I had a doc tell me in June of '95 that I had a good six months, probably a year left (and the guy was trying to encourage me). He was honest but he was wrong. I can handle the truth. And I know how important hope is. But sometimes we grasp for straws because the hope we have is based on false information. I'd rather have hope based on truth.*

*I think there will come a time when more treatment doesn't make sense. I'll know when and it will probably be intuitive. I know I don't want to be bed-ridden for very long. Being comatose is not being "alive." And I don't want that either. When I see that coming then I will forego treatment and let God/nature take its course. I have a good doctor who respects my wishes and will tell me if he has anything more in his bag that will offer me what I want. I want to be active as long as possible. The best illustration you can give is Cardinal Bernadin of Chicago. He was active in his ministry until the last three weeks of his life. That's what I want. It will be my decision alone because my family and medical help are all hurting because of me. They want the same thing that I want. They are hurting watching me get worse and worse.*

*Some will say we're not fighters, but you and I know that's not true. There comes a time when we recognize reality. When we know we've given it everything we had.*

This chapter's emphasis on the failure of hospital medicine to deal with dying in a humane way is intended as cautionary, but there are still excellent resources out there. Many physicians are extremely sensitive to these issues, and are able to help their patients make wise choices, and come to terms with what is happening. And they understand the crucial importance of expert palliative care. As Dr. Kathleen Foley of Memorial Sloan-Kettering Cancer Center writes:

*In the real world in which physicians care for dying patients, withdrawing treatment and aggressively treating pain are acts that respect patients' autonomous decisions not to be battered by medical technology and to be relieved of their suffering.<sup>18</sup>*

Caren Buffum wrote of the moment when her doctor gently raised the issue of stopping treatments with her for a second time:

*I sit in the doctor's office, perched on the examining table—my feet dangling like those of a child.*

*"New tumors in the liver."*

*Three times is not a charm—it's scary. Three scary reports. For the second one, I was in a hospital bed and Stephen [her oncologist] said that sometimes it's okay to let go. I know he wasn't telling me that I should, but he wanted me to know that I had permission.*

*"I know," I said. We hadn't talked about this before. It had never been the right time. Was it the right time now?*

*I then saw two clear paths ahead of me, cutting through the rest of my life. One was very short: the treatment didn't work. The other disappeared over a hill.*

*The short one had a name: "Going home to die." But when I left the hospital, I didn't know which path I was on.*

*Now comes the third report. Stephen once told me there would always be something else to try. But I guess he meant if I really wanted to ... if it was worth it ... if all things weighed in that way. Now I understood. It wouldn't always be worth it.*

*Stephen asks me what I want to do next. He understands my need to make choices. He knows what I will say. But does he know why?*

*He worries that when the time comes to let go, I won't. I will suffer because my fists are clenched too tightly on a life that isn't mine anymore.*

*I worry that Stephen thinks this. I want him to know something—I want to see peace in his eyes.*

*I am not desperate, I tell him. I am not afraid to die. I do not cling to life out of fear. But I have too many reasons for sticking around. I need at least two years to get my musical produced.*

*Two years! I can see the horror on his face. Does she even know? he is thinking.*

*I want to laugh. Of course I know. So what? I want two years. I demand two years. So there!*

*At home, I realize what I have done. I have taken my life back in my hands again. In the hospital I had raised it to my feeble lips, like a dandelion puff, and blew it down the road to let the wind carry it along whichever path it drifted over. Then I had given the short road a name and dared to peer down it, thinking that if I saw its end, I could rest.*

*There is a peace in having looked, but I am not ready to gaze down that road. I have chosen the other path.*

*I'm glad Stephen and I talked about "things." Hopefully it has set his mind at rest.*

## **From holding tight to letting go**

In her next message, again philosophical, Caren updated her friends:

*Four weeks ago, I was letting life slip out of my hands—God, I was so tired of hanging on so tight. Two weeks ago, I grabbed life back again. Yesterday I got some so-so blood tests. Slip—And scans next week—I haven't a clue what that will do. Even with symptoms, I find it hard to believe there really is in my liver a "thing" as big as the space between my doctor's hands when they are spread six inches apart. So the battle feels like it is really between my will to live and my willingness to die.*

But a month following that, in late May of 1996, Caren felt sure that she was indeed entering a new stage in the process.

*Last night I took another hard look down that other path. I have been having persistent pain in my right side, about where I believe my enlarged liver sits. My appetite has been seriously depressed, and with all the other symptoms, I have been wondering if I need to get serious about doing the things I know must be done in my lifetime.*

*I was feeling very discouraged and shared my fears with Dave. He agreed that the symptoms do seem to point in one direction (first time I wished he hadn't been so agreeable). And he found it scary too.*

*I was up very late—the pain made it hard to sleep. But also, I didn't want to let go of Dave. I do not feel ready to let go.*

*I understand more and more why Stephen keeps reminding me that non-treatment is an option. How many cases like mine has he seen? People who are undeniably on that path, and it is just a matter of time? He knows that in each case, the length of their lives was not seriously altered by the choices of treatment and that the main difference is quality of life. So he is wondering, I'm sure, if I will understand this enough to preserve my quality of life in the end and not sacrifice it for the dream of a miracle cure.*

*But still, he and I are investigating options. Doesn't every cancer patient hope there is that as-of-yet undiscovered cure just around the corner? And as I have told him, I enjoy so much in life—as long as I can continue to enjoy my life, I want to stick around.*

Two months following that, in early July, Caren wrote that she and her family were beginning to prepare themselves:

*I saw my doctor yesterday and he said all the signs point to liver failure, and there is nothing we can do. There will always be other treatments available, but either they are pretty wimpy at this stage or will make me very sick and impact seriously on the quality of whatever life I have left. I guess the bottom line is that*

*he is talking in possibly weeks ... but sometimes docs get it wrong. And I do believe in miracles.*

*But Dave and I have talked openly and honestly with our sons and other family members and friends, that I probably don't have a whole lot longer. It feels weird to finally talk about it in practical ways. There are things we have to take care of. And then there are those things we want to do as a family and as a couple that we will aggressively try to accomplish. A dear friend in Seattle is trying to arrange a trip for me to visit them out there. My heart's desire is to go overseas one last time, primarily to Israel, but that certainly seems out of reach. So we are trying to come up with family things that are doable—a few days at the shore, a visit to old stomping grounds in New England, camping, a concert or show, special meals, etc. We've asked the boys for ideas for things they want to do with us all together. I have been very tired, a symptom from the liver problem. Typing this is very difficult—my fingers won't cooperate, and I keep falling asleep mid-sentence.*

*As the reality is setting in, Dave has become more initiating, more comforting. He's moved from being helpful to being heartfelt. If nothing else, this stage of the disease seems to be bringing us closer together. I am doing "okay." Surprisingly calm, and I think that is a supernatural gift from God. I have my "good" cries and then next minute laugh at my own morbid jokes. My faith is continually being strengthened, and while I don't know how I will handle tomorrow, I am thus far able to handle today.*

Caren handled her remaining days with grace and courage. A month later, surrounded by her family and a couple of close friends, she died peacefully at home. At her memorial service, her husband, Dave, spoke about her last day, how members of their congregation and friends had come to say their good-byes, how the music Caren had composed was played and people came to sing her the songs she had written, and how their youngest son, Levi, pointed out to them all how his mother had died with a smile on her face.

It would be cruel to suggest that everyone can or should face the prospect of dying with such equanimity and acceptance. To believe this is only to perpetuate the “nobility” myth that pervades much of the literature on terminal cancer, the prettied up image of the brave, uncomplaining cancer patient who slips away quietly, determined to inconvenience no one. We all hope that when it is our turn, we'll be able to face death bravely and calmly—but in the interim there are many deep feelings of fear, anger and regret to be confronted.

Some of the anguish and bitterness felt by metastatic breast cancer patients as treatment fails and pain and disability increases is eloquently expressed below by Sandra Yandell. Now 33, and first diagnosed when she was only 27 years old, Sandra had just celebrated the first anniversary of a grueling fifteen hour surgery to rebuild a spine shattered by metastases.

*I went shopping a few days ago, and in the main aisle the store had a wonderful display of potted flowers. They were all so lovely, but I settled on a miniature red rose and a fluffy purple hydrangea. I thought it would be so nice to have some life*

*around me, something bright and colorful and cheerful. They were looking a little sad late yesterday, so I watered them and hoped for the best.*

*Last night I had a terrible time sleeping. Everything just hurt—back, shoulders, pelvis. I woke up crying about 4:00 a.m. and took another MS Contin (I usually take one before bed). I was still pretty groggy when I got up this morning, and it made me a little late to chemo. The office was incredibly busy today, but I talked to my doc briefly after I finished my chemo (Navelbine since August). I took a bus home in the rain, and I was okay until I got home.*

*I took a look at my flowers and burst into tears. I can't keep a plant alive, how can I keep myself alive? My tumor markers have shot back up, doubling since my last test. My doc is additionally worried about the bone pain, which she says would be consistent with a failure of the chemo. I don't want to do this anymore. I'm so tired. A year ago I was still in the hospital, and back problems started almost a year before that. I can't remember what it's like not to hurt, not to be sick, not to be pale and tired and empty. The really sad part is that I was feeling so optimistic, hopeful that maybe it would stop for a while and let me go on with things. I even had the audacity to start growing my hair out again. I don't want to make any more treatment decisions, I don't think I can face nausea and neuropathy and hair loss and on and on. It's a horrible nightmare that I've been stuck in for almost six years, a nightmare that continues to cheat me and rob me of health and life and time. How much do they have to cut out of me, how many poisons do they have to pump into my body? How many pain pills will make the hurt go away?*

But even anguish as wrenching as this, having found its expression, tends to be short-lived, especially when the loving support of friends and family is there. A few days later, Sandra wrote:

*Just in case you're wondering, my hydrangea is hanging in there, and I'm going to put it in a bigger pot tomorrow. Sometimes a change of location and scenery can do wonders. The miniature rose, however, looks totally dead, but a gardener friend said that he can put it into dormancy and in three months or so I can have it back and blooming. Pretty amazing, if you ask me. I guess it helps to listen to an expert sometimes, because other people can see things in ways that I can't. A different perspective, a sunny window, a little care...it's incredible how things look when you change them around a bit.*

## **Hospice and palliative care**

In 1995, the National Cancer Institute spent only \$26 million dollars, or slightly over *one percent* of its budget, on research into pain control, quality of life issues, palliative care and hospice. Although they are supposed to represent the highest standard of care, only half of the nation's fifty NCI-designated cancer centers even offer hospice programs. Only one third of the half million cancer patients who die each year receive hospice care, 90 percent of them at home.<sup>19</sup>

Hospice physician Fred Schwartz believes that attitudes are changing around such issues as:

*...the rules and regulations governing insurance, health care in the last six months of life, who is appropriate to be aggressively treated versus not appropriate. These are money issues that will be looked at as money becomes the driving force in health care, because hospice is less expensive, as well as more humane.*

*The comment that all of the health professionals on our team get constantly—nurses, social workers, doctors, home health aides—is “Why wasn’t I told about your services six months ago, three months ago?” And it’s the last day, or week of their husband’s life or father’s life. “Why wasn’t I ever told that this existed?” they say, or “Why did the neighbor next door have to say, ‘Gee, why don’t you contact a hospice?’”*

New York oncologist Dr. Samuel Waxman presents a physician’s perspective on hospice, which reflects the inconsistencies of a medical system that doesn’t handle these issues well.

*Most hospitals are not equipped for dying. You have to go through the legalities of signing a DNR, and other procedures. All of that gets in the way. There’s just no simple answer. The best places to die are terminal care facilities. With home hospice, I am often dealing with an agency and nurses I don’t know. It’s a voice on the other end of the phone. Sometimes it’s amazingly good; sometimes it’s not. The family is the best source of knowing what’s going on. When hospice works, it’s fabulous, and I am quite relieved to have a patient being handled at home. I think it’s better. But it’s individual. With an older person with very little family support, it’s too much to ask. With little children involved, it’s very hard.*

*It’s very easy for a physician to just turn things over and get out of your sight. You don’t have to sit and explain things, and hold hands. It takes a lot of time, a lot of time, and I believe physicians are getting very disgusted with the system out there, by how they’re being treated by the business community, being shown a lack of respect, a lack of loyalty. People whom you’ve taken care of for years are suddenly on a different plan and you can’t even see them.*

*Hospice physicians are not generally that accessible to me. I tend to work with the nurses. I want to have the continuity with my patients, and handle their needs. I’m just saying that I don’t like turning over my patients to terminal care facilities unless I know them. If they’re in home hospice, I don’t want to say good-bye until I have to. And it bothers my patients, too. Sometimes it gets a little complicated, because they are seeing other doctors, and they don’t know the patient, they’re just treating the pain. So it can be a problem, but it tends to be the best way.*

Fred Schwartz explains his perspective as a hospice physician on the issue of which doctor is primary in this situation:

*My role is basically symptom control. If somebody is well tied into their own doctor, either at the office, or if their doctor makes home visits, then we really*

*don't directly interact, unless the physician asks us for some advice or to act as a consultant. This happens a great deal. Many times the doctor will say, "I don't know how to handle the pain, but I want to maintain a relationship with this patient. Can your doctor order the pain medication?" And usually I will do a home visit and just be a consultant on that patient. Other patients are just not tied into their doctors, or the doctors don't do home visits. Maybe some of their recent care was in a tertiary hospital like Sloane-Kettering and they live out in Eastern Queens and the trip is overwhelming. At that point, they will ask me to become involved. I get involved with about 50 to 60 percent of our patients. I become primary physician for them.*

"Doctors keep doing things the same old way," says Dr. Joanne Lynn, director of the Center to Improve Care of the Dying at George Washington University, and one of the authors of the SUPPORT study, mentioned earlier in this chapter. We are only beginning, Lynn says, to deal "with the fact that no matter how long you save a life, there's still a death in store, and that that part of life should be good, too."

What services does hospice offer? Schwartz describes what his team does:

*Once a family makes the decision to stay at home, they need that support, that physical support and emotional support—for patient and for caregivers and the larger family unit. For the patient, the first priority is symptom control. Get the pain, the nausea, the agitation, the anxiety, the constipation or whatever the symptoms are—get that under control. Nobody in agonizing, writhing pain wants to talk about God or what's going to happen to their spouse. From the patient's perspective, symptom control is the cornerstone that allows you to go into those other, deeper areas. We usually say that our hospice team can provide emotional, psychosocial and spiritual support. So what does that mean? It means that we try to see people holistically. It's not only that they have a pain where their liver is pressing on something, but also, what's going to happen to their retarded daughter when they die, or how is their wife of fifty-five years going to adjust to the new situation, or who's going to take care of their dogs when they die? Or whatever their issues are.*

Breast cancer patient Barbara Quirarte, a hospice volunteer in Bandon, Oregon, describes what hospice does, as she sees it:

*The aim of hospice is to provide comfort to a dying patient and the family. This includes the physical, emotional, mental and spiritual aspects. There are so many areas: getting mental comfort for a patient by a volunteer attorney for legal matters, taking the patient's children to the newest movie, arranging for hospital bed and other items to ease the patient's home comfort, picking up prescriptions, taking the patient for a ride to the beach, and talking and talking and talking about whatever the patient needs to talk about, as well as the patient's family and friends.*

*The most important job is pain management. If this isn't accomplished, hospice has failed. Intractable pain is often what traps a patient in a hospital. When a hospice nurse visits, one of the things she evaluates is the pain level and arranges*

*for whatever is needed with the doctor. As a volunteer, it is my job to report pain immediately to the nurse. Not just the pain the patient tells me about, but the unspoken pain too. Often the patient doesn't want to "complain," or doesn't realize that there are other drugs to help, or can't take what she has because it upsets her stomach but doesn't want to say anything for fear of being a bother. Also, the body language of a patient gives one a clear indication of unspoken pain. We look for that, talk to the patient, call the nurse, the nurse contacts the doctor, the doctor prescribes, the nurse or volunteer gets the medication and delivers it to the pharmacy or patient. If it doesn't help in 12 to 24 hours, further steps are taken. Very often it is the hospice nurse who first realizes a morphine pump is in order, since he/she sees the patient much more often than the doctor.*

*Our hospice coordinator once told us that 90 percent of the patients that say that they "just want it all to end" are the ones in extreme physical pain. Once that pain is diminished, the quality of life immediately picks up, and the patient no longer wants it all to end.*

Quirarte does express some cautions, however:

*Unfortunately, not all hospice workers, doctors, nurses are good pain managers. Everyone in hospice gets to know who really cares about the patient's quality of life, and who doesn't. If the time comes that I am terminal, I know which medical personnel I want on my team. Unfortunately, a patient and family usually don't know, and go into this situation blind and pretty much at the mercy of everyone else for their quality of life—unless the patient has an advocate. We have the knowledge to advocate for ourselves, but there comes a time that we need someone else to step in for us.*

Dr. Ira Byock, President of the Academy of Hospice Physicians, believes that dying can be a relatively gentle process, but only when there is sufficient support. For home hospice, this means that there needs to be a committed family member or friends who are willing to be full-time caregivers. The hospice team—nurses, physicians, social workers and pastoral counselors—are expert in the control not only of pain and other distressing physical symptoms, but also in relieving the emotional suffering that goes along with all the impending losses. There are five simple but powerful statements that every dying person can say to, and hear from, their loved ones, Byock believes. They are:

*Forgive me, because in any relationship there are mistakes that need to be forgiven  
I forgive you, for the same reason.*

*Thank you.*

*I love you.*

*Goodbye.<sup>20</sup>*

## **Final gifts: Six stories of dying**

Death is the great mystery. We regard it with fear and fascination, as well as overwhelming grief. We deny its inevitability and avoid its approach. Despite the growing hospice movement, the dying are still largely hidden away in hospitals. Many of

us have never seen a person die, nor do we allow ourselves to think about what our own deaths might be like. We are inclined to agree with Woody Allen, who once quipped: "I'm not afraid of death. I just don't want to be there when it happens."

Yet for our own peace of mind, it's important to demystify the dying process, to understand how ordinary families get through it. Six husbands of women who died of breast cancer have agreed to share their stories, reproduced here at some length.

## **Bob Crisp, talking about Ginger's death**

Ginger had been failing rapidly when Bob wrote how she and he were facing the prospect of additional treatments:

*I'm not ready for this in several respects. My approach to problems is persistence and it's paid off for me in the past. I've never been close to a decision like this, so everything is new. I'm not ready to accept the "no hope" aspect of the decision. I know that many people in the past have tried to hang on for the possibility of a magic bullet cure. And, however remote, the possibility hangs heavy.*

*Ginger is closer to the "no more treatment" decision. She has kind of worked up to this. It started with statements like "At some point there may be a time when the treatment problems and the chances of success are so low, that I will not want to continue." This statement has moved to ever stronger stages where now it's "no treatment unless someone can show me that it won't degrade the time I have left and it has a reasonable chance of success."*

*I have to let Ginger get there in her own way. For my part, I can't go to her and say something similar to "Face reality, no treatment's going to work, the cancer is spreading, it's only a matter of time ...days, weeks, months..." Sometimes a person wants the response: "Don't give up, there's always hope...." I would rather go down in flames trying something than to play it out for a few extra months. However (big however), I could never be sure until I face the situation and have gone through as many ordeals as she has.*

As he had throughout Ginger's illness, Bob allayed his own anxiety by trying to research what they might face next. There wasn't much available that was specific enough for him.

*The possible paths that may be taken, what they may look like, how long, how painful ...I could not find. Kind of funny that you can't find something on how a person dies from breast cancer. It would sure be helpful for me. I may go talk to her oncologist as he told our daughter (my step-daughter) that it might "get ugly." She did not ask and he did not give any more detail.*

More and more, Bob was aware of feeling a certain sense of distance from Ginger.

*I also see an emotional separation that angers me at myself. Yet I know it's my own defense system working to protect me. I have been grieving since April of last year.*

*I still see the future and she does not. This seems inescapable under these conditions. I can talk and dream of a trip, say to Russia, and know it's something I might do. She can't talk or dream of something like this, as she knows it's not likely. It's a weird place to be. Sitting around with friends, it's easy for me to say something about something I would like to do... but it's different for her. However, I do notice that she will talk about something on or for the house that may be in the future and it will hit me that I hope she is here to see it. When the reality is most likely: I live, she dies, then it's weird. Probably because you have always talked about the future from the same position. Now it's different. Just weird, can't give you a better description.*

A month later, Bob reported their meeting with the oncologist.

*She asked him about what was ahead and he talked about some physical problems she would encounter. He did not offer and she did not ask about time. If she had wanted to know, she only needed to ask. This is as much as she wants to know as of now. Or that is my reading of it. I think she wants to know what to expect physically in the next few weeks and nothing more. This was the product of months of working our way through this and sensing what Ginger wants and seems not to want. Ginger is not shy. Recall she can be a hard-ass lawyer: one of my friends described her (in legal work) as meaner than a one-eyed water moccasin (old Arkansas expression). So if she wants to know something or talk about something, then she can be quite forceful. We've had many discussions with doctors along the way. She has been detailed in asking about what/how long, etc., on treatments. Her mortality has been brought up on several occasions. Here, she does not ask for detail or more specifics. In the fifteen months of fighting this thing, she has been consistent in not asking about "how long do I have."*

*Ginger has not "stopped treatment." She is open to anything that might help and not have serious side effects. Not many options, but I think she prefers this to the "official stop procedures." I think that takes away the last glimmer of hope and she is not ready for this step. I think she will get there, but in her time, which is what I want.*

*She has withdrawn somewhat. She's afraid of losing it emotionally. She does not want to be alone. She wants to do this in the way she thinks it should be done: with dignity, with faith, courage, respect.... In doing so, she hides (suppresses) some emotions.*

Two months later, Bob wrote that he was now ready to describe Ginger's death:

*The days before Ginger died were very difficult. A week before she died, she started to lose contact with us. We only had a couple of short conversations after that. The last five days were essentially no contact. There were a couple of times where she seemed to indicate an affirmative to wanting some water or similar items. But she was still there internally. She would get very agitated at times and try to move and get out of the bed. At first, it was hard to restrain her. I know that she was in a panic state—not knowing what was happening. We would talk to her to try and calm her. This might go on for fifteen minutes or longer, even an hour*

*at times. The frequency, duration and intensity of these episodes diminished with time. I'm sure the reason for the diminution was that she was too tired to exert herself for any extended period of time. Her pulse rate stayed in the 130+ range and sometimes went up to as high as 180.*

*We had someone with her around the clock and worked in shifts. I tried at first to stay up as I was afraid of being asleep when she died. After two nights, I realized I could not take this pace and started to sleep some, about four hours a night. The others promised me they would wake me if it looked like she was near death. The morphine pump was a problem in that we had to keep giving extras. It was the only way to keep her calm. They would increase it after we told them of what happened. But it always seemed to be too low to avoid agitation until about the last twenty-four hours.*

*She took nothing for about five days: no liquids, other than a few drops of water from a straw that we offered as much as she wanted. She had problems with congestion in her throat and lungs that caused difficult coughing. It was very difficult to watch her try to cough and not have the energy to clear the congestion. We had a suction pump to clear the congestion from her throat, but she resisted it and it was hard to get her to accept it. It helped a little.*

*Her two daughters, Kathy and Ann, and I took on the primary responsibility of any decisions regarding morphine, etc. They wanted her more sedated than I did. These circumstances are difficult as each person has an opinion of what should be done. I'm trying to forget the interpersonal aspects of this as they were done in difficult circumstances. It was a difficult time.*

Bob was somewhat reluctant to describe what happened on the day Ginger died.

*I don't know if this is something you will want to read. It's not pretty. The death process is ugly, but mixed with some items of beauty and love. I won't be offended if you choose not to read or stop along the way.*

*It was my first time to see someone die—never happened to me before. We had just a little warning as the person sitting with her noticed that her breathing was slowing. The rest of the family asked me if I wanted some time alone with her and I said yes. I thought the time was close but thought it might go on for awhile, and I told them that I would sit with her and then let them have a few moments alone. Her breaths were spaced apart by several seconds—long enough that after each one you wondered if she would have another. And then she didn't have another breath. I checked my watch and waited a minute and knew she had died. I checked for a pulse and nothing. She just stopped breathing—nothing else. I waited a few minutes alone with her and then went and told the others.*

*The hospice nurse came first. She is also a deputy coroner and can sign a death certificate. She was very good—knew exactly what to do and things went smoothly. It took about two hours for the funeral home to come and get the body. By that time, several friends had come whom we called. Before the funeral people came in, we sang and danced to the song "Lord of the Dance." It was*

*spontaneous and seemed right. Then the funeral home people came and I asked to help load her body. We put a plastic type board under her body, wrapped the sheets around her and they covered her with a blanket. Then, again I asked to load her into the van, so I pushed her out and loaded the dolly into the van. I watched it drive away. Immediate cremation was her wish so I knew that was the last time I would ever see her remains.*

*My emotion was primarily one of relief—that her pain and suffering was over. That nobody would ever stick another needle in her arm, or cut on her, or do radiation, or chemo. This emotion of relief stayed with me for several days through the funeral.*

*Now, I've moved into the sad phase. The reality that she is gone is setting in. That all the dreams will never be. That she is gone from this life and I must go on.*

When asked how he might advise others who are forced to face the death of the one they love best in the world, Bob reflected,

*I think you show up and do what is needed. Be present in a loving and caring way. It will be emotionally and physically exhausting. Try to pace yourself, as it is a marathon and not a sprint. You can't stay at someone's side for that many straight days. Get some time alone, take long showers, sit outside alone, be close but get some relief. And, listen to your soul and do what you need to do, not just for her but also for yourself. You have to go on and it's important to follow the path where there will be less regrets. I have very few regrets, but I did a lot of things my way, which is not necessarily the right way.*

## **Gerry Wirth, talking about Cindy's death**

*In September and early October, Cindy was getting severe headaches. Somehow everyone thought that it was due to rotting teeth, and she even had two removed. But the pain persisted. It was discovered she had three large tumors in her brain. The whole illusion of normalcy started to crash down.*

*What happened during the following months was very perplexing and painful at the time. Cindy was preparing to die. She became very withdrawn from us. Her life consisted of doctors, hospitals, watching TV at home, and that was it. She was extremely hard on the kids, it was as if she was trying to raise them in the short time she had left. But the worst thing was that I did not see it for what it was. I just reacted to the actions, not the process. My love for her and compassion were at an all time low because I did not understand what was going on. I now believe that she was withdrawing from us so the process of dying and meeting God would not be as painful for her.*

*I still took the kids to Cub Scouts and gymnastics. I had to spend a lot of time outside of the house because Cindy's tolerance for the normal noise children make was very low. Cindy did not seem to mind being alone, and the kids loved*

*being able to be children. Somewhere during this time the cancer killed my wife even though she still could breathe.*

*Cindy's parents had to come back. They felt extremely guilty about leaving. About as guilty as I felt for hiring such a lousy sitter. They were wonderful . They relieved my worry about child care and allowed me some peace of mind when I was at work. They also helped me to buffer Cindy better from the children. I am so disappointed in myself about not having the strength, wisdom and insight to allow me to demonstrate my love for Cindy to the end. I got tired.*

*I did not have much emotional support. I have been contemplating that for the last several weeks. I did not have support, not because people did not care, but because I did not know how to ask for or accept it. During the bulk of Cindy's illness, we relied on each other for support. It seemed like the rest of the world was much too pessimistic for our tastes. In retrospect, they were probably more realistic. Because of this perceived pessimism we only accepted "physical support." Help with the kids, house, cooking, etc. Emotional support was not allowed. When the time came when I could use it, no one was used to giving it.*

*It is a mistake I hope I never make again.*

A few weeks later, Gerry was more philosophical about what had happened, although his regret about not saying good-bye is a litany that runs throughout his narrative.

*I lost Cindy sometime in January. She knew the end was near and started withdrawing from the living and preparing to die. Many people I have talked to say that this is normal. What would have been tragic is if I would have lost her in October of 1991 when she was diagnosed. We both know many people who die on the day they are diagnosed with cancer and the rest of their lives are spent waiting to stop breathing.*

*Cindy, and I guess myself, did everything we could to live and enjoy the four years that followed. She raised her newborn daughter into a confident, caring four year old. She gave my son a love of nature and books. Most importantly, she taught me how to be a good, patient and loving father. We went camping, to Disney World, to museums, zoos, parks and theater. We enjoyed our friends and everything about life.*

During the final weeks of Cindy's life, Gerry recalls not being able to comprehend what was really happening.

*Cindy was becoming less able to walk or function. She would get from her bed to a chair in the living room and back to bed. Sometimes she was even too weak for that and stayed in bed. She had no patience for the normal noise and bickering that children do and she was very hard on both of them. Cindy's folks were staying with us, helping with her and the kids and letting me go to work enough so I would not get fired. I tried to have things as normal as possible for the kids while making things comfortable for Cindy.*

*I found out later that she said good-bye to some of the office staff who had been a special part of her treatment over the four years. They were not willing to accept it and admit the fight was over. I wish I would have been there so I could have picked up on this. It might have prompted me to start my good-byes.*

Clearly, though, Cindy had prepared her family for her death in other ways. Gerry recalls Cindy's careful instruction about caring for their children and the house. In the last months of her life, she was teaching him how to cook.

*Cindy was extremely patient. She would tell me over and over how to do things. She would even write down checklists. Most importantly, she would never criticize in a negative way. It was always, "this is okay, but if you try this it might work out even better." I did not always do these chores cheerfully, I was trying to build a new career in the company, but Cindy rarely let my sullenness affect her gentle guidance.*

*The last thing that she taught me was how to make pizza. Both our children loved her homemade pizza. She taught it to me in December. I had to carry her from the chair in the living room to the kitchen so she could keep an eye on me! I will never be one quarter the homemaker she was. But whatever I am I owe to her.*

Gerry described Cindy's last week day by day.

*Tuesday, February 6. I came home from work and visited Cindy. She was okay, lucid and had been given several neurological tests. I went home for supper and brought the kids back to visit in the evening. She was not all that interested in seeing them. Another sign I should have caught. We did not stay long, as she was tired.*

*Wednesday, February 7. I went home to eat, and returned with the kids. She did not even want them near her, as she hurt so badly and they were wanting to hug and hold her. We did not stay very long and I told the kids to say good-bye. I knew I would not bring them back as long as their mother was like this. I did not want them to have that memory of her.*

*Thursday, February 8. Again the same pattern, except at 9:00 p.m. the nurses called and said I should come to the hospital as her vital signs were weak. Cindy's mom and I rushed over. Her mom stayed until 11:00 p.m. She then went home so she could get the kids ready for school in the morning. We felt as much normalcy as possible was best. I stayed the entire night, just holding her hand and napping in a chair. I was not smart enough to talk to her.*

*Friday, February 9. On Friday morning her oncologist came in. He said there was nothing else that could be done. She should be sent home to wait. And he was going on vacation. I knew there was no hope left, but I did not want her to die at home in front of the kids. I convinced the doctor to check her into inpatient hospice. There is never a good time for an oncologist to take vacation. It just was so devastating as Cindy and I had so much faith in his compassion.*

*I went home and slept two hours and then tried to find an inpatient hospice. It was a nightmare. My insurance required hospice care to save money. Inpatient hospice is hard to find and thus limited to one week. Everyone thought Cindy would linger. Additionally, all the hospice "counselors" tried to make me feel guilty for not taking her home. Finally, one of the nurses in the oncologist's office used her connections to allow her to stay where she was at hospice rates. Cindy's father went home on the pretense of signing up for his Social Security retirement benefits. I believe he did not want to be here for the end.*

*Saturday, February 10. Saturday was my day to be with, and try to support the kids. I took Courtney to her gymnastic lessons. Matt had earned free pizza at Pizza Hut for reading thirty books, so I took them to lunch there. It seems ludicrous I did these things on the day Cindy died. I visited her in the afternoon and evening. She was drifting in and out of consciousness but never really lucid. I just held her hand and wept. I got home at 7:30 p.m., exhausted. I only had had four or five hours of sleep in two days. I was about to go to bed at 8:30 p.m. when the hospital called again. Cindy's breathing was labored, I should come.*

*I did not believe she would die that night. I was upset because I was so tired but went anyway. When I got there she was breathing very hard. I sat with her and held her hand. I whispered my "good-byes" and "I love you's" in her ear. I sat in the chair and dozed off until 11:00 p.m. When I awoke, I decided to get some coffee so I could stay awake with her. I was gone for ten minutes. When I returned, the room was very quiet. I thought her breathing had gotten better. Only slowly did I realize that she had died. I waited thirty minutes to ensure she was gone before I called the nurse. We had the proper DNR papers, but I wanted no arguments.*

*I was furious with myself. For four years I was with her through as much as I could, but I was not there at the end! Others have told me that sometimes they wait until you are gone to die, especially if you have not let go of them. I do not know if this is true. But I wish I would have been there.*

*I made the appropriate calls, her mom, my folks, and went home. As I left the hospital, a selfish sense of joy and relief came over me, as I knew it was over and I would not have to come back! But it was also a lonely walk to the car.*

Looking back, six months later, Gerry's regrets were transformed into advice he hoped to pass on to others in the same situation.

*Cindy took her last two chemo treatments to please me. She had given up. Those treatments were very painful and I do not blame her for not wanting them. The ironic part about it is that I encouraged her to take them because I thought that she was still fighting and just needed encouragement.*

*It is hard to know when to acknowledge the fight is over. I wish I would have so we could have said good-byes before she lost lucidity. Not knowing if she heard my final "good-bye" and "I love you" is one of the two things I regret still and probably will until I die. If you can somehow communicate this so others will not*

*make the same error, it would be very helpful to those left behind. We focused so hard on fighting cancer that I waited too long to say good-bye.*

*Fight as hard and as long as you can, but know when to say good-bye.*

The rituals Gerry observed on important dates, however painful, helped him to work through his grief.

*I decided to go to mass in the morning and then stop at the cemetery to place a bouquet on her grave. I thought that marking the day in that way would help. It didn't. My pain and grief was as strong as it has ever been. I wept over her grave for an hour. It is a good thing it was 7:00 a.m. and the cemetery was really closed. I wept for all the times I did not understand her enough. I wept for all the times her children will not have a Mom at a special day. I wept for myself, and the loneliness that is always with me. And I wept because I cannot even order a grave marker that I feel is special enough to mark her final resting place! I am not used to indulging my pain in this way, but on that day I did.*

*Others have told me that there will be another in my life some day. I do not believe it will ever happen. How can I ever find someone with whom I have shared so much?*

*We celebrated her birthday, too. Because our anniversary and her birthday are so close, we always postponed the big celebration until the anniversary. But we always did something special on her birthday as well. Usually we went out for ice cream at a special store in town. Matthew really enjoyed telling the waitress it was his Mom's birthday. We went out for ice cream in the evening. Matt asked if we could. For some reason he wanted to celebrate. When he asked I did not think I would enjoy it. But I did.*

*Our anniversary, June 23, was much better. This year I took the kids to a water amusement park. I went with another couple, the Jacobs, from school. They knew it was our anniversary and would not take no for an answer. It was a day of total distraction. But seeing all the kids have a great time gave me a warm feeling. I am not sure I am doing a good job as a parent. I try the best I can, but there are always doubts. Seeing them have a good time, like before Cindy died, helps to give me confidence.*

*For me life goes on. There is a huge hole in my life, but the pain is subsiding. What I miss most is someone to share things with. Triumphs, decisions, work, quiet times. Many people who lose a spouse say they are not really gone, just there in a different way. I envy those, for Cindy is very far from me. But yet she is all around. The needlepoint pictures on the wall, the dinner recipes I cook. Her gifts live on, her companionship is missed.*

## **Chris Tribur, talking about Candace's death**

*My wife had two recurrences, one shortly after HDC. Up until the last, I refused to acknowledge the inevitable. We never discussed it and, in fact, my wife quickly*

*became incapable of discussing options and so I made all the decisions, including a final one to cease treatment that will haunt me the rest of my life. To the best of my knowledge my wife did not wish to cease treatment, and I certainly did not want to let her go. I think when the time comes, the choices narrow themselves and we do the best we can. These are extraordinarily difficult circumstances to find oneself in, but we do what we do and there is no value in second-guessing or beating oneself up after the fact.*

*I took her to the Cancer Treatment Center in Tulsa, where they ran a battery of tests. She deteriorated steadily. One night she had an episode where she flung herself out of her wheelchair and started shrieking at me incoherently. I took her to the inpatient floor of the tower comprising the CTC and they admitted her. She became incontinent, developed labored breathing and was in a near comatose state. The docs took me downstairs to x-ray and displayed the hundreds of CT scans we had brought from Denver with us. They showed me that one of her lungs was completely filled with fluid and the other was spider-webbed with tumor. She was admitted to intensive care.*

*Late the night of the 3rd of July 1995, they called in a pulmonary doc. He told me they could drain the filled lung, but her blood count was so low, that she could bleed to death. He recommended doing nothing. They put her on a morphine pump. I sat and stood by her bed frantically pressing the infusion button every time she stirred in discomfort.*

*On the 4th, I called my sister-in-law Helen, who was staying with the girls in Denver, and suggested they fly down. Helen stayed, and the girls came. Candace's oldest sister and her husband had already driven up from Georgetown, Texas. Zoe visited her mother one time in ICU and wouldn't return. Miri stayed with me up to near the end. When Candace started to go, Miri reacted rather violently and I grabbed her and left the room. My brother-in-law called us in our room to tell us Candace was gone. The girls and I departed the next morning for Denver.*

When Chris read a message from another husband about the importance of discussing end-of-life decisions and saying good-bye, he expressed both skepticism and regret.

*My wife and I never really dealt with this and she was the one who did the pulling away. I fault her for nothing, I only regret that we didn't really come together to face the inevitable. I think we could have emotionally held onto each other lovingly, instead of existing in "bubbles" of denial. Second-guessing in my situation is futile and destructive. I just wanted to say I admire you for your clarity and wisdom.*

*Every circumstance is different. I don't know what her choice was. She made no overt indications of her wishes. I speculated that she may have subconsciously or unconsciously thrown in the towel as early as April. Maybe earlier, I don't know. Without spoken direction from her, I was dragged reluctantly to the final stage. I didn't want to give up.*

*I had no help from anyone. I had a feeling that people (family, doctors) were stepping back from us. I felt kind of abandoned. I agreed to no more treatment a couple of days before she died only when it was spelled out in black and white for me. I suppose everyone should have a "living will" or something comparable. But I saw no clear-cut place prior to the time of my decision where one could, in good conscience, "pull the plug." If she had looked into my eyes and said, "No more, Chris," it would have been different, maybe. I don't know. Calculating intellect has very little place in this scenario, in my opinion.*

*She had the services of a pain specialist while in ICU. At one point after the morphine pump was hooked up, a nurse said they wanted to make sure she didn't get "too much." I snapped back, "You've got to be kidding!" I had already agreed to no further treatment, and the attending physician said several times to me "I have a bad feeling."*

*I don't think you will find two circumstances or two individuals who will react the same in such circumstances. I regret I didn't do more at an earlier time. I go back over the whole chronology and second-guess everything! Her favorite oncology nurse reacted to the news of her death, "but her prognosis was excellent!" My wife's older and favorite sister holds her oncologist responsible for letting her cancer get out of control. I don't know what to think. The only comfort I have is that my wife was tired of fighting and seemed to let go on her own. She slipped slowly into a child-like state of mind, where she looked forward to almost fantastic, dreamlike plans for the future and stopped looking back at the harsh road she had traveled.*

*All in all it was not a neat and tidy affair by any stretch of the imagination. I felt out of control most of the way.*

## **Scott Kitterman, talking about Mary's death**

As Mary's cancer worsened, Scott, who had researched exhaustively and played a major role in treatment decisions, was finding it hard to let go. Describing his state of mind, he wrote that he was coping with "plenty of denial."

*I'm still subconsciously convinced that there's a way out of this. When my mother died of breast cancer in '83 we had a good six months warning that the end was coming. I was convinced that I had prepared myself emotionally for her death. I was really wrong. Hit me like a ton of bricks anyway. So, each time a brick lands on my head I just do my best to shrug it off and move on to the next one. It's not easy, but once again what other choice do I have? You can't really cushion yourself from the blows.*

Although he'd encouraged Mary throughout to continue in treatment, and fight the cancer aggressively, Scott was also aware that there would come a time when further treatment would be futile.

*We knew a month or two ago that the chemotherapy regimen she was starting then was the last one it made any sense to do. We had looked through things then—there were some things in Phase I trials, but nothing that was even in an NCI sponsored trial. Mary wasn't interested in an option that bought her a few days or weeks. If it wasn't measured in months, she wasn't that interested in it. She would have liked something measured in years, but it didn't work out that way. That's the first thing, in terms of how her wishes went. She was very aware of how this was likely to turn out, and had thoughts in her mind about what was reasonable to do and what was not.*

*We didn't always agree 100 percent on that, and there were several times during the last seven months since she was diagnosed with recurrence that she'd say, "Well, it's time to give up." I'd say, "No, not yet—these things it makes sense to do." And she'd say she'd go on.*

*The problem is that when you are undergoing some form of chemotherapy, and it looks to be effective, you just don't know how long it's going to be effective.*

*What finally happened was that about three weeks before she died, she got what turned out to be her last chemotherapy treatment, and that night started having some unusual pain.*

*The doctors discussed with us going back to methotrexate, which was the first intrathecal (in the membrane surrounding the spinal cord) chemo which she'd had back in March. She'd been on that until the disease had gotten resistant. So they said, "We can go back to that, and give it three days in a row, rather than just one, and see what that does." Based on her feeling, she didn't want to suffer if it was going to just give her a few more days.*

It was the news of this latest recurrence that caused both Scott and Mary to make their decision.

*When they gave her the news that the cancer had come back, she looked at me and said, "I'm ready." And I said to her, "It's time." One of the things that amazes me in my own reaction to all of this is how quickly I flip-flopped. I was always the one banging my fist on the table, saying, "We need to go on, we need to do the next thing and keep going." But based on what we'd agreed on, about how you made these decisions, it was obvious that we were at the point where we were done. There was no doubt in my mind that that was the point where we were at. There wasn't any in hers either. We'd always been researching and looking for options, and we knew that the chemo she'd been on was the last one that made any sense. We hoped we were going to get more time out of that, but we didn't.*

*Mary said she wanted to die at home. I didn't know how I felt about that. My only prior experience with a close family member was when my mother died of breast cancer in 1983, and she had died in the hospital, so I had never dealt with that.*

*I was a little worried about having Mary here. She wanted to come home so that's what we did. End of discussion. Once she got home, it turned out to be just fine. I really felt quite comfortable with it. We both slept in our bed. It seemed almost*

*normal a few moments at a time. It was certainly physically and emotionally easier not to be divided between taking care of Mary at the hospital and taking care of Sylvia (our daughter) at home. One of the things I'd been going through was that when I was at the hospital, I wanted to be home with Sylvia—she stayed in day care during the day, and I saw her in the evenings. When I was here, I wanted to be with Mary. Bringing Mary home ended that feeling of being divided. That was an important thing for me. It gave Sylvia a chance to see her mother again.*

*The one difficult problem we had in getting Mary out of the hospital was in the area of pain control. She was on the morphine pump with the button you push to get more, but the thing that kept happening because most of her pain was spasmodic, she was on a very low basal rate, and then most of the morphine that she got was in bolus form. Because her disease was progressing fast it was very easy to get behind the power curve on that. They had ordered additional morphine for IV push. When you needed that, it told you it was time to raise the amount of morphine in the box, but then you had to get orders written for that, and that takes time. On top of that, she'd have really bad ones, where no amount of morphine was going to make any difference. So in those cases, they had Ativan, which is similar to Valium, and that just put her out, to sleep. Sometimes that was the only way to get her out of that pain. That was fairly successful. There was kind of a step hierarchy that you walked through to try to manage it, and you always knew if you gave her the Ativan, that within thirty seconds she'd be asleep, out, and at least not feeling the pain. But that's the problem. Morphine and Ativan are closely controlled substances, and they don't like to give out morphine, except in the PCA pump, and they certainly don't like to give out Ativan either. That was the one area where we had trouble with the going-home part of it. In the end, we worked it out okay.*

*Hospice was very helpful. As it happened, we didn't need a huge amount of help. Mary's mother came and stayed with us, and I was here, and my father came and stayed as well. There were plenty of people in the house to help out and do things. I am very comfortable, more than most people would be, in doing a lot of the medical things that needed to be done.*

*Before we brought Mary home, I had a little talk with Sylvia. She's not even three yet, so she has a limited understanding. She really doesn't talk much yet—she's got a little speech delay. Something to do with stress in the family, I think.*

*She'd been to see Mary in the hospital. Whenever Mary would feel like giving up, I'd always take Sylvia to see her and she'd change her mind. Not particularly fighting fair, but it worked. She understood, and had been sick herself in the hospital, so she thought, well you go to the hospital and you get better.*

*I said, "Sylvia, this time Mommy's just not going to get better." She got very sad, but then, like any two year old, five minutes later, her mind was on something else. So when we brought Mary home, Sylvia was a dear. She went up to her Mommy and hugged her, and lay down with her and wanted to be with her. Sylvia*

*was scared by her, and she couldn't stay there for a long time, but she spent as much time as she could deal with.*

*She wanted to know what she could do to help. It really impresses me how well she has dealt with all of this. I felt it was important to keep her as informed and involved as could be, given her age.*

*By the time we got home on Friday, Mary really couldn't talk anymore. She was awake and aware, and obviously knew where she was. She could occasionally get a word out. There was some confusion. She was on a fair amount of morphine by then and the cancer was progressing. She was Catholic, so we had the priest come in and give her last rites, while she was still aware of what was going on. We made sure that the spiritual aspect of it was taken care of.*

*People called and said, "Well, maybe I'll come by next week." I said, "Look, this disease has always been very aggressive. It's moving fast. I don't know how long it's going to be. So if it's important to you to see her before she's gone, I wouldn't wait. Come now." It got progressively worse over the next several days, with less time when she was conscious and more time when she was basically asleep, although even when she was not obviously conscious, you'd see evidence that she was aware of what was going on around her. Until the point she died, I think she was aware.*

*By Monday, she had fluid in her lungs. First it sounded as if she was snoring, then it got heavier from there. We sat her up and that seemed to help. She had IV fluids, to keep her hydrated. Her kidneys were starting to shut down as the disease progressed. Tuesday she was worse, and we put her on oxygen that morning, and just about 1:30 she stopped breathing, and her heart stopped beating and she died.*

*At the end, it was very quiet and peaceful. One of the things she had told us was that she wanted her mother and me with her. Just a couple of minutes before she died, she opened her eyes just a slit, for the first time in about 12 to 18 hours. It was almost as if she was checking to see who was there. I'd been downstairs because her mother was saying a rosary with her, and I left them their privacy for that. Something just told me it was time to go upstairs. I'm not sure why. But she opened her eyes a little bit, and her breathing just gradually got a little more ragged, a little more ragged, and just stopped. Then a couple minutes later, the color went out of her face and her heart stopped.*

*I called the hospice people and the funeral home and they pretty much took care of everything from there. I'm sure that some of how I feel right now is masked by shock, because it's only been just over a week. But I do feel surprisingly at peace with the whole thing. I miss the hell out of her, and I cry sometimes.*

*The key thing is that now, looking back, I don't have any feeling of regret: damn, if only we had done this. We did the things that there were to do. We researched the hell out of it, to make sure we had explored our options and knew what all of them were. It tears me apart, what happened, but it was going to happen. There*

*was nothing else that could have been done about it. That's another thing that makes this different than my mother's death. There are some things that should have been done differently in her case. So much has changed in pain control. Then it was, "You can't have your shot. It hasn't been four hours yet." Morphine's been around for a hundred years.*

*The person going through this has a lot of ups and downs. It's very easy for them to get despondent and depressed and give up. One of the things that's important is, even if you know how things are probably going to turn out, to keep some hope alive that maybe, that's not going to happen. What Mary had was rare and there wasn't a lot of current research about it. We had to do research by analogy. We always had a hope that if we could just get this thing beaten down pretty thoroughly, there was something that might produce some kind of durable remission. Hope was present with every kind of chemotherapy we tried. It was only the week before her death when we realized that the last chemotherapy had failed, that we realized that that wasn't going to happen. And so throughout the whole seven months, we knew what was probably going to happen and what we hoped was going to happen. Keeping that hope alive is critical.*

*I'd always heard people say about dying, "Oh, it was nice and peaceful and she was surrounded by her friends," and so forth. I never believed that was possible. But that is basically what happened. It was surprisingly calm and peaceful.*

*Somebody asked me, "How are you going to feel if she dies in your bed?" I thought, well, I'll just buy another bed—Mary wants to come home. I haven't felt the need to do that yet. I may change my mind over time, but I slept in the bed that night after she died.*

## **Chris Leach, talking about Pat's death**

*Pat was anything but a stoic cancer "patient." Her medical knowledge (she was a psychiatric nurse) of course was a mixed blessing. It kept her busy and gave her a certain degree of satisfaction to be informed on the different options that were available and under research. But that same knowledge also reinforces some aspects of the disease that might better be pushed back into the recesses of the mind somewhere.*

*Regarding her "calm" reaction on hearing the news of her brain mets, I don't think she changed in any significant way during the last months. Although now that I am reflecting on that thought, I think it is safe to say that she did seem to change somewhat as far as her acceptance that she (we) were running out of options. But once again, she did not change at anytime to the extent that she became someone else. Her reality in all its splendor was with her and us right up to the second she died.*

Pat and Chris, who loved to travel together, had decided to take a final trip up the California coast, visiting friends and family, and stopping along the way for the constant transfusions Pat now needed as the cancer spread through her bone marrow.

*That would have kept me from going on any trips. But with Pat it was different. Since we knew pretty much where we were going, I and she made phone calls with her oncologist's help, and set up appointments for blood transfusions in San Diego, San Francisco and Eureka, California. As we traveled up the coast of California, I would stop to tank up the rental car and drop Pat off at a hospital to have her blood tanked up.*

*We left San Diego and flew up to Marin County. Pat received a couple of units of blood at Marin General Hospital. We visited relatives, and visited a woman that Pat had met on the Internet. Again, I noticed that Pat seemed to be moving a little slower, getting tired more frequently, but still getting the most out of each day. She even seemed to be enjoying dining out but not with the same gusto as in the past. By the time we got up to where our son lives in Arcata, her blood counts were dropping to the point that it looked like it was dangerous to go more than three days or so without a transfusion.*

*On or about August 13, she called Dr. Susan Rabinowe, her oncologist in Hartford, Connecticut. Based on that call her doctor said we better get home as soon as possible. Susan tried to keep a positive spin on it by suggesting that we were already gone for three weeks and had seen everyone so that should lessen the disappointment. Actually I was glad we were going home, I was nervous to say the least. We drove the 280 miles from Arcata to San Francisco, caught a red-eye to Hartford arriving at about 12 noon the next day, Thursday, August 15. We went directly from the airport to St. Francis and Dr. Rabinowe. I thought at the time that she would examine Pat, give her a couple of units of blood and send us home with the expectation that we would come back in a few days or so. That was not to be. Pat was admitted to St. Francis that day and there she stayed until I brought her home on September 5. That first night was the only time she was alone up to the day she died on September 11.*

*The next day I went back to St. Francis, and with the exception of two nights when one of the children relieved me, I camped out in the hospital room with Pat. As I said earlier, she was never alone. She had a steady stream of visitors. It was actually peaceful at night when just she and I were alone. The nurses and nurses aides loved her. I learned some nursing skills myself. Pat was pretty much incontinent, I took care of everything 90 percent of the time before the nurses ever responded to the bell. We actually had some tender moments, if you can imagine that.*

*A critical event, by the way, is the issue of pain. Pat, understandably, had said on several occasions that her biggest fear was pain and suffering. Mercifully, she never experienced significant pain. Shortly before we left for California she had been having some fairly annoying pain in her neck, shoulder and hip areas. Even that disappeared. Her demeanor became relaxed, even when she wasn't on Ativan or other medication. In fact she did not take much in the way of medication the last couple of weeks at all. The memorable thing is and was her sweet smile. One of the reasons they all loved her in the hospital was that she was incredibly*

*solicitous of others, especially with that sweet smile that was her lifelong trademark.*

*The attending physicians were very helpful. It became pretty obvious that Pat probably was not going to get better. I knew it, they knew it, but it didn't matter in the end, we simply loved her, stayed with her and waited. It was, I think, a case of mutual understanding that we were on the homestretch. We never really said, "Well, I guess this is it, honey." We just knew, and simply stayed close together the whole time.*

*I had, by this time, talked with several of the doctors, given them Pat's living will. It was her and my intention that extraordinary intervention not be used just to keep tissue alive. She, myself and the children agreed that we did not want Pat to wind up being a medical experiment. A CT scan of Pat's head was called for to see if her mental foggiess was caused by the low blood counts or possibly cancer impinging on her brain. Pat and I were alone in her room when the doctor announced that the CT scan confirmed that the cancer was, in fact, now pressing into the brain. Pretty heavy news, I'm sure you will agree. In the past Pat had reacted, again understandably, pretty strongly to far less devastating news. This time she looked at me very calmly and simply said, "Well, that's not what I had hoped for." And that was the extent of that.*

*The kids were driving up to Hartford every day. Not surprising, they and, needless to say, I loved her to an unimaginable degree. Stephen flew home just a few days after we did, by the way. He canceled the whole semester at Humboldt State so that he could be with his mother. We were happy about that, not that it would have been any other way.*

*Back to the results of the CT scan. It was at this point that we made the collective decision that no further treatment, other than palliative medication for pain if necessary, would be given. Pat wanted to be at home, so on September 5 I took her home. We got home early afternoon, it was a beautiful day. She sat outside in her wheelchair with the sun, kids and dog for a couple of hours. We set up the hospital bed in the living room, facing the picture window, trees and birds. The next day, Friday, we were able to get her outside again when the hospice nurse came by to do her interview. She almost completed it when we had to bring her in because she was getting tired. In the meantime, friends, neighbors, relatives were streaming in and out all of the time. More food than we could eat. We allowed anyone that wanted to be with her to do so. By the time Monday rolled around, Pat was pretty much sleeping all the time. It was getting harder to get her to take any liquids. But again, thankfully, there was no sign of suffering. We kept her comfortable. But still it was the worst time of my life. The feeling of helplessness was overwhelming.*

*We kept trudging along, waiting. We had reached a point where we were whispering in Pat's ear to let it go, that it was okay, let it go. On September 11, Wednesday morning, my oldest daughter was alone at Pat's bedside when she called to me that Mom was breathing strangely. I listened to her chest with my*

*stethoscope, checked her pulse and told Kathleen that I think this is it. In a matter of minutes after saying that, Pat simply stopped breathing. I held her hand, caressed her head in my arms and cried my eyes out.*

*Pat died at 11:20 a.m. I called hospice, and they came over in a short while. In the meantime all of the children, Pat's mother, the hospice nurse gathered around, and an hour or so later I escorted Pat to the van, and from there she was taken to the crematory.*

*Hospice was wonderful. By their own admission they did not have to do very much because the kids and neighbors had things so attentively under control. They told me they had never seen such love and family support. If they weren't just trying to be nice I guess that is a very nice compliment. But they sure were there if we needed them. They have been following up to see if I need any support as well.*

*Pat's physicians were honest and straightforward. Other than that I did not feel they had any real involvement, certainly emotionally anyway, other than assuring me that they would be sure they did all they could to keep Pat from suffering.*

*What was helpful was the care, concern and relationship we had with the hospital staff, and ,of course, the love and support—ongoing, I might add—of family and friends. I honestly cannot think of any significant things I would do differently. We are just very lucky that we have the kids and friends that we have.*

*The advice I have for others is just that: invest your love now and you will not have any regrets later.*

*We bought a little plot at the local cemetery. I brought a small tarp. They let you dig your own hole for ashes. I took an antique family silver teaspoon, gave each of the kids a clear plastic 35mm film container and half filled them, using the spoon, with Pat's ashes. That way they could each take a small portion of their mothers remains and do what they liked. I then put the remaining ashes in the hole, put the silver spoon, Pat's wedding band, and, removing my wedding band, placed that in the hole also. Then each of us sprinkled soil over the ashes and objects, Father Kevin said the burial prayers, and we all went to breakfast.*

Seven months after Pat's death, Chris sent this update on their family.

*Our daughter Maura had a beautiful baby boy on December 19. He is now almost four months old and the cutest, most lovable little creature that God ever created, or however those things happen. So I am now a grandfather, consequently my accolades for my grandson may be somewhat biased. My oldest daughter, Kathleen, is due to deliver her first baby this July 12.*

*The only really sad part about the new baby is, of course, Pat's memory. It was the one major "milestone" she did not make. I have to admit, I am starting a few tears writing this part. When Ryan was born, we all had the same thoughts, namely, "If Pat could only have been here for this." Knowing how she felt about*

*her own kids, we knew all too well how she would have reveled in joy over the grandson she never got to see or hold.*

*But life, as they say, goes on, and you can be sure that any grandchildren we have will hear much about the wonderful grandmother they never got to see....*

## **Glenn Clabo, talking about Barb's death**

As I was finishing the final editing on the manuscript of this book, Glenn Clabo wrote that his wife, Barb, had fallen ill with very rapidly progressing multiple tumors in her liver, that had recurred after some months of remission following her high-dose chemotherapy. After consultation with her oncologist, Barb decided to seek no further treatment and to die at home. Within a few weeks, she was gone. When I went to pay my respects at the funeral home five days after her death, Glenn and their close friend Phyllis Dalby, a nurse who had been with the family throughout, sat down with me and recounted what had occurred. Although Glenn and Barb's children, Jamie, 20, and Chad, 18, didn't take part in the interview, their role in her last days was central.

Glenn spoke first of what led up to the last day of Barb's life.

*In my eyes, how we got to the day was basically our life. It wasn't just a moment of discussing our feelings with each other. We were spontaneous most of our life in our relationship. What really got me to that day, and how it all evolved, was this: When Barb got diagnosed, when we found out the cancer was in her liver, we were talking about treatment and how far she really wanted to go. One of the things that really got me upset was that she was concerned she wouldn't do enough, or that I wouldn't think she did enough. That really made me mad. We talked about it, and never really resolved it.*

*Three or four months later, after the bone marrow transplant, when she was pretty much well, we sat around for a day or two and forced ourselves to talk about a lot of things. One of the things I told her was that I was really mad about that. I told her it was okay with me when she wanted to die. It was like this huge thing came off of us, and she said, "I promise you, when it's time, I'm going to go. But when it's time, it's my time." I said, "Fine, I want you to understand...don't stick around just for me...don't fight on for me."*

*How the day evolved will help you to understand a little better. I basically knew what was going on. I had done a lot of research, finding out how this process happened. We talked with the doctor that Monday, and he told us, step by step, what was going to happen.*

*The night before, I stayed up, just talking to Barb. She was in and out. She would stay awake for a few minutes and then just fade off for a half an hour, or an hour. It was hard to wake her up, and at about 4 o'clock, I couldn't feel a pulse. She wouldn't respond to me. I got up, went out and got a drink of water, and came back. I kept talking to her. Her pulse would go real low, and then she'd just come back. Then about 6 o'clock, she woke up and started cracking jokes. That's when*

*I realized she was fighting it, that she just didn't want to let go. We needed to do something to make her comfortable, to make it okay.*

*She was in our bed, and she just didn't want to be there. She wanted to be out in the living room, on the couch, in her favorite place. The sequence was: we went from the bed, then we took her and put her in a chair and sat her in the middle of the room, in a chair with wheels, because we never got the wheelchair, then we moved her to my chair, the Lazy-Boy. We basically had to carry her. We put her in that chair and she didn't like it. So finally, I just picked her up and put her on the couch. She wouldn't lay down. She was still in and out, and when you moved her, it really brought her down. Her pulse just basically went to nothing. She just sat in her spot on the couch, sitting up, for five hours, semi-comatose.*

*Phyllis came in when I was in the computer room, taking a break. She told me Barb's medical status, and said, "Glenn, maybe you need to talk to her." So I went out into the room, and talked to Barb, but I never really had the feeling that she wanted me to talk to her. She really didn't want to hear what I was saying, that it was okay, that she could let herself go. I never really felt comfortable with it. There was something wrong. And this is where it starts getting really weird. I still haven't figured it out.*

*One thing that was bothering me was that everyone sat in the living room, just crying, moping, touching. It seemed like they were even embarrassed to laugh. Jamie came up one time and said, "This is not what Mom wants. We've got to lighten this up."*

*I sat on the couch for a long time, got very tired, and finally got up and said, "It just isn't time." I went off with Phyllis and another friend out on the deck and we talked for maybe half an hour. During that time, Barb was comatose, I would say. She was moaning, a continuous moan, which was probably her voice box relaxing. Then Jamie came out of the house and said, "Dad, she's calling you." Maybe she was...I don't know if she was, but she looked like she was just saying "Glenn" very rapidly.*

*So I sat in front of her and hugged her. Chad was on one side, and Jamie was on the other side. And I very slowly said a bunch of things. It wasn't planned. It wasn't a thought. It just came out. It was how I felt. I think the real key to the whole thing was that I kept saying everything was okay, "I'm okay, Jamie's okay." But what really was the key, what changed things and let her relax, was when Chad said to her, "I'm okay, Mom. I promise I will be okay."*

*I say it was cosmic, and it really felt beyond human...because she very slowly just stopped moaning, as I kept talking to her. I told her, "Barb, everyone's going to cry. We're not going to cry for very long, and we're all going to be happy again. I promise you that." And she stopped breathing, and some of the people in the room began sobbing and screaming. And I just sat there—and she started breathing again. It was almost like they scared her awake. I kept on saying, "Please, I told you...please...everything is okay. I told you they were going to cry. Don't let them scare you. Everything is okay. They're going to cry, but they're*

*going to laugh again.” And she basically calmed back down, and she stopping breathing. She just died, sitting up.*

*I got up, and to be honest with you, I didn’t know where the hell I was. I still don’t know what I was feeling. Probably I felt every emotion in the whole world. I didn’t even feel like a human being. I went in the bathroom and I was just sitting there. When I came back out, the kids were on the deck and everyone was saying good-bye. I went up to my kids, and I said, “Let’s not treat it like it’s the end. Let’s treat it like it’s the beginning. Just carry on with what she wanted us to do.” And we are. I see a huge difference in my kids. This whole thing has changed us altogether, especially my son.*

*It was perfect. I almost feel it was out of some kind of romance novel...*

At this point, Phyllis offered some of her impressions:

*Glenn asked me if he was romanticizing what happened. And I said, “No, not in my opinion.” I have never seen anything like this. I feel privileged to have been a part of it, really. The amount of love and trust between Glenn and Barbie was something so rare in life, to see that between people. Glenn loved her enough to be able to let her go, to do what he had to do. And that Barbie trusted him enough to listen to him, and to believe him, and let go. That was so obvious.*

*The first time Glenn talked to Barbie, they weren’t ready. Maybe he wasn’t ready, and she could sense that. But then, as things got worse, to me she seemed very torn. She wanted to go, but she couldn’t. She was hanging on. There were no vital signs at this point. She was moaning...and the people with her, the family, were getting very upset. People kept asking me, “Is she in pain?” I said, “I don’t think so. I just don’t think she wants to let go.”*

*Glenn just kind of walked over to her. I had the feeling that he was a man with a mission. He knew what he had to do. He knelt down between her legs and put his arms around her. He said everything right. I don’t know where the words were coming from. Even when he was talking to her at the end, it was not morbid at all. He even made a few jokes. As he talked to her, you could see her visibly relax. That sense of torment that she seemed to have just went away. He said to her, “Relax, take it easy, go with it, it’s okay. We love you.”*

*I just feel so blessed to have been able to see something like that. I don’t think I will ever see something like that again—that kind of love and trust between people. Glenn was so open and welcoming all the time. That’s not always true with families. Any friend who wanted to come by and see her and spend time with her, the door was open. She did have good friends come by and hold her hand. She was surrounded by love.*

*They say that the hearing is the last sense to go, and that it’s very intense when someone is dying. In the three days I was there, we joked and called her “satellite ears” because she’d be in the bedroom, and people would be talking quietly in other parts of the house, and she’d hear them. Friends would be visiting, and she seemed so out of it that they started talking a little bit louder, and she’d say, “Oh,*

*stop talking so loud.” I’ve seen that with other patients, that their hearing became much keener.*

*One of my fondest memories was the night I got there, she was lying in their bed, and I lay down beside her. She kept going in and out, falling asleep. But she said to me, “This is the end, isn’t it?” I said to her, “Barbie, you have a little bit of time, but not too much. I guess you know that.” “How much time do you think?” she asked. I said, “I really don’t know, but if there’s anything you want to tell me....” She started talking to me about Glenn. She said, “I know nobody will ever take my place with Glenn. We’ve been together for so long.” (He was 13 and she was 15). She said, “I want you to make sure he gets some companionship. He’ll need a woman. And I want you to talk to Jamie. Don’t let Jamie scare her away.” I said, “Have you already talked to her about that?” She said, “Yes, I have. But you might have to talk with her, too.” I said, okay, and I will encourage Glenn when he’s ready.*

*Such incredible love. That night, she was in the bathroom, having a hard time. She was very yellow, and her stomach was swollen with ascites at that time. She could hardly walk, and she couldn’t toilet herself. She was crying and saying, “I’m sorry” and “I look so terrible.” It was what any woman would feel with her husband. He put his head in her neck, and nuzzled her, and said, “How beautiful you are to me. I love you.” And he meant it. And she settled down and let us help her. In his eyes, she was still beautiful.*

As the interview ended, Glenn reflected:

*I am sitting here and amazing myself. I’m doing okay. Twenty months ago, I thought I was going to go nuts. I’ve been preparing for this, I think, for a long time. But it’s weird. Everyone’s telling me what a beautiful thing it was. But I just talked my wife into dying. It’s a strange feeling. I just talked my wife into dying, and everyone is telling me that’s beautiful. If you had told me that two years ago, I would have called you absolutely crazy. But I’m not the man I was then. It’s amazing how my whole mindset is different.*

*I prepared myself for her death, but I didn’t prepare myself to be doing that. I’ve been trying to figure it out. I know what I said. It wasn’t planned. It just came out. Phyllis had mentioned earlier: “You know, you may want to talk to her.” But I don’t know how it all came about—it just happened.*

*But I’m also torn, sitting here saying my wife is dead. For thirty-four years we were together. And I am feeling relief—well, it’s not relief, but kind of like I’m at peace. To me, that has to be what people work for. It’s something that they have to work for before it all happens. Don’t wait until the last second and try to cram it all in. That’s really what happens. It’s never a good time to talk about death, no matter when it is. When you’re first diagnosed, you don’t want to talk about death. When you’re feeling well, you don’t want to talk about death. When you’re not feeling well, you don’t want to talk about death. We forced ourselves to do it.*

*People look at me a little funny when I say, “Everything went perfectly.” But if I am going to die, that’s the way I want it. We were there. Her best friend was here. Her father and brother were here. And there she was, sitting in her place.*

*I realize that I’ve been very busy for the last week. I was alone in the house one day...and, well, Jamie’s going to leave eventually, and Chad doesn’t live there anymore. I know it’s going to be hard. I haven’t prepared myself for that as much as I tried to prepare myself to make sure that everything was resolved. All the little things we needed to say, were said. Her last words were, “I love you.” I will never forget that, and neither will the kids.*

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*Notes:*

- <sup>1</sup> Lipstein, Owen Loss: an interview with Froma Walsh Psychology Today, Vol. 25 ; No. 4, July, 1992. Pg. 64
- <sup>2</sup> Charmaz, Op. Cit. Pg. 81-82.
- <sup>3</sup> Yalom, Irvin D. Existential Psychotherapy New York: Basic Books, 1980. Pg. 31-32.
- <sup>4</sup> Colburn, Don. The Grace of a ‘Good Death’ Escapes Many. The Washington Post, December 5, 1995. Pg. Z07.
- <sup>5</sup> Callahan, Daniel. Pursuing a Peaceful Death. The Hastings Center Report, July, 1993. Vol 23., No. 4. Pg. 33.
- <sup>6</sup> A Controlled trial to improve care for seriously ill hospitalized patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments SUPPORT. Journal of the American Medical Association, JAMA, Vol. 274, No.20, November 22, 1995. Pg. 1591.
- <sup>7</sup> Too Many Americans Die Alone, in Pain, Attached to Machines. The Robert Wood Johnson Foundation, <http://www.dash.com/netro/nwx/tmr/tmr1295/death1295.html>
- <sup>8</sup> Callahan, Daniel Once again, reality: now where do we go? Dying Well in the Hospital: The Lessons of SUPPORT. The Hastings Center Report, Vol. 25, No. 6. November, 1995. Pg. S33.
- <sup>9</sup> Nuland, Sherwin B How We Die: Reflections on Life’s Final Chapter New York: Knopf, 1994. Pg. 257.
- <sup>10</sup> Ibid., Pg. 223
- <sup>11</sup> Ibid., Pg. 234
- <sup>12</sup> Callahan, Daniel The Troubled Dream of Life: In Search of a Peaceful Death New York: Simon & Shuster, 1993, Pg. 51.
- <sup>13</sup> Skelly, Flora Johnson The good things about death. American Medical News, Vol. 35, No. 40, October 26, 1992. Pg. 41.
- <sup>14</sup> Ibid., pg. 41.
- <sup>15</sup> Nuland, Sherwin B. Op. Cit. Pg. 258-59.
- <sup>16</sup> Ibid. Pg. 228-9.
- <sup>17</sup> Broyard, Anatole, Intoxicated by My Illness and Other Writings on Life and Death New York: Fawcett, 1992, Pg. 57
- <sup>18</sup> Foley, Kathleen M. Competent Care for the Dying Instead of Physician-Assisted Suicide. New England Journal of Medicine, Volume 336, Number 1, January 2, 1997.
- <sup>19</sup> What is Hospice? Boston Globe, June 20, 1996.
- <sup>20</sup> Ibid.