

CHAPTER ONE



First Days

At night, after the patients are tucked tightly into their beds, there's a hush in the hospital hallways, and you can hear bad news coming a long way off. A tousled young doctor, rounding on his hospitalized patients after completing his office appointments, charges down the corridor with loafers squeaking on the polished linoleum floor. He stops at the nurse's station, double-checks what he'd been told on the phone by skimming a note in a chart, and then ducks into the room of an 80-year-old woman. Despite the late hour, her two middle-aged daughters are still restlessly perched on plastic chairs by their mother's bedside, dejectedly watching the curled-up woman sleeping. The doctor waves at them to join him in the hall. "As you know," he says breathlessly, "when you brought your mother to the emergency room yesterday for severe back pain, a transvaginal ultrasound found a mass on her right ovary and she was admitted to the hospital for more tests. The results of the laparoscopy conducted today to take tissue samples of that mass aren't good." Pausing, he gives each of them a sympathetic look before stating quietly, "Your mother has ovarian cancer. It's a Grade 2, or moderately aggressive, tumor. Probably spread beyond the ovaries. She'll definitely need more surgery." He pauses again and declares, "I'll do all I can to arrange the best care for her. Do you have any questions?" They stare back at him in shock and shake their heads. He

then excuses himself and takes off down the hall, white lab coat trailing behind him like a fleeing specter.

The daughters stand there stunned. One gapes, the other cries. They clutch each other's thick hands and say nothing. Years from now, they'll recall the moment as the demarcation point between what they had been—a normal family with an aging but vivacious mother—and what they are to become: an injured, grieving family. Serious illness always arrives with a shock as if a ship, having long drifted on slow currents or glided through open waters, runs up suddenly on unseen rocks. Even among families that face crises with determined upbeatness, there's an initial shudder of fear as the structure of their lives totters. Even family members of a fatalistic bent, who constantly peer ahead for the next bad thing to come, are thrown backwards by the jolt. Even in families in which a parent's age should prepare the daughters for some medical event, a doctor's pronouncement of illness rattles everyday routines with a rumbling crash.

The daughters lean heavily on the railing that lines the hallway wall and slowly begin talking in the low whispers of girls sharing secrets out of Mother's earshot. Though they're both in their fifties, one is 5 years older than the other, and under the moment's duress they revert to the patterned behaviors of big and little sisters. "We've got a lot of things to do. We've got to think things through," the older one says in a pressured tone. The younger one gazes at her expectantly. But the initial shock has given way to only uncertainty for them. What did the doctor mean exactly? they ask themselves. How bad is it really? Did he rush away out of haste or fear of telling them too much and painting too bleak a picture? This is followed by a set of more immediate questions: Are we supposed to tell our mother the test results? Or should we let the doctor tell her tomorrow and then make believe we hadn't known? Their father had died of cancer; won't that make it harder for Mother to handle her diagnosis? And what if it's wrong—should they get a second opinion before saying anything to their mother? And then a third set of pressing questions occurs to them: How can we leave her tonight knowing she has cancer? But what would our husbands think if we don't come home? Are we daughters first or wives?

They hear a couple of nursing aides laughing near the unit secretary's desk. The hallway is otherwise a quiet, lonesome place. The older sister goes into her mother's room momentarily and then comes out again and begins pacing slowly. The younger sister watches her and

nervously licks her glossed lips. In all other life crises, they'd look to their mother for guidance. Now, following the doctor's whirlwind visit, that's no longer possible. They're already feeling the loss of the mother they've known.

In antiseptic institutions and offices, during anxious hours of night and day, scenes like this play out. For physicians, they are challenging problems for which biomedicine prescribes evidence-based treatment paths. In a case of cancer, the doctors will consider the type of tumor, the organ in which it's located, and whether an older patient is hardy enough to withstand the arsenal of possible treatments—surgery, chemotherapy, and radiation. But for most people blindsided by a diagnosis, the news occurs against a backdrop of personal and family histories and evokes feelings and associations that have little to do with organic pathology. It's not just that they don't understand the science behind their life-threatening disease. It's that the threat brings those lives into sharper focus. Their memories and dreams, now more vulnerable, seem suddenly more vivid to them. Their relationships with family and friends, revealed as fragile, seem more crucial.

In the morning, when the mother wakes up, she's greeted by her physician, looking studiously somber, rounding again before his office hours. She glances at her bleary-eyed daughters now slouched in the plastic chairs as if they'd spent the night in them. (They actually went home at their husbands' requests but made sure they returned early so they could be present when the doctor delivered the news.) When the doctor clears his throat and announces in a low voice that her tumor is ovarian cancer, the mother stiffens and then sighs. He goes on to try to explain the specialists he's contacted and the surgery she'll need—at the least, to remove her right ovary—but she's already too preoccupied to hear much of what he says. In those first moments, myriad questions pass through her mind: How much of me will they cut out? Will the pain be bad? Who will take me to the doctor's office? Who will clean my apartment if I get too weak? The physician glances uneasily at her daughters, who nod back slightly. Then he mumbles goodbye to the older woman before making a quick exit again. She's staring toward the window and doesn't answer him.

Over the next hour, the mother and daughters converse sporadically, with long pauses. Her roommate has already turned on her TV, and the cheery tones of the commercials make a surreal background for

their gloomy thoughts. The breakfast tray comes, but the mother hardly touches it. She expresses her thoughts in a gruff, even voice that her daughters know she's always used to try to cover all fears. She looks at them hard with her dull blue eyes several times as if trying to gauge whether she can fully depend on them. The makeup on their tired faces is askew, but they appear attentive and concerned. The thought occurs to her that she'll ask no more of them than what she once gave them freely and feels she deserves now—setting aside their busy lives for a while to give her their undivided attention, just as she did, as their mother, for them and, as a wife, for her dying husband.

As the day wears on and her shock begins to fade, the wild multiplication of cells within her still receives little of her thought. Instead, she worries about whether she'll be well enough to make Thanksgiving dinner for the extended family and whether her sons-in-law will resent that her need for care will deprive them of their wives' time. Lying still in bed with her wrinkled face sagging and her silver hair flattened and mussed, she sifts through her past, recalling what it was like for her when she was a child and stared at haggard old people hollowed out by cancer. She wonders what her grandchildren and great-grandchildren will be thinking while watching her in the coming months. She ponders her late husband's choices in his fight against the dread disease, remembering the graciousness with which he faced his death. She feels fresh grief that he can't be there at her side to help her now.

In those moments during that morning when the daughters feel their mother's eyes upon them, they each experience a surge of compassion and protectiveness toward her but also a mild discomfiting shame. Each of them senses intuitively that the serious illness of a loved one brings a kind of reckoning for every family member. Close relatives, especially, feel the press of the tribe's prime rule: Be there in the hour of need. How family members respond to the call to be at the hospital, provide money, or give up their jobs to take a sick parent into their home becomes a measure of their loyalty and love. Though no request has yet been made nor arrangements discussed, the daughters are already aware their mother is taking note of whether they meet or turn away from her plaintive gaze. She'll surely judge them, they figure, for what they do or don't do for her throughout her illness.

The conversation lags, the TV drones, and the lunch tray arrives without fanfare. The daughters notice that their eyes seek out each other whenever they awkwardly sidle between the bed and the tinted window in their half of the tiny room. This is due partly to the unspo-

ken commiseration and camaraderie between them. They look at each other with sad but knowing expressions as if to say “We thought it would be hard if it ever came to this, and it is; we’re in this fix together now.” But their looks take on a wide-eyed cast at times as if a question hangs in the air for which they need reassurance from each other: Are we really in this together?

What does it mean to be a family caregiver? In some instances, it may initially entail doing a few chores for an aging relative who can no longer take care of her home entirely on her own. As that loved one continues to age, you may be expected to incrementally do more and more for her over time. In other cases, being a caregiver means having to provide 24-hour total care to someone who’s been suddenly stricken with a serious illness that has disabled him utterly. In nearly every instance of family caregiving, siblings and other relatives have to negotiate means of tending to their loved one while dividing the labor in a way that feels fair and equitable to everyone involved. Even in the most trusting, committed, and communicative families, there’s always some question about who will come through and for how long—not just during the initial crisis but in the months, and possibly years, that follow, when care continues to be needed. When family members don’t come through for one another, let alone for the patient, the resulting anger runs deep. Like shared memories of failures to give wedding presents or atrocious behavior at funerals, they recall the disparities of caregiving effort for decades. The hard feelings can harm family relationships beyond repair.

These sisters have always managed whatever conflicts arose between them and were able to cooperate well during their father’s decline 10 years before. And yet, more jarring than the crackle of the hospital’s paging system, doubts intrude on their thoughts now. The younger one knows her older sister’s husband has been set on doing some traveling. Will her sister feel pressure, she wonders, to leave town and Mom? But the younger sister also knows her older sister’s inclination to take over situations, and she doesn’t want her to grab the glory of doing the bulk of the caregiving. The older one realizes her younger sister has a new grandchild she hoped to baby-sit. Will she sit with their mother as well? The older sister also has long been critical of her younger sibling’s passive tendency to let others take the lead. Everything they know of each other’s lives—their temperaments, circumstances, and entrenched habits—becomes one of many

variables to be weighed in an attempt to discern their caregiving future together.

Here's where the undercurrent of shame comes in. For all their concern about the other's willingness to give care, these daughters are ambivalent about the sacrifices they feel obliged to make. They do want to help their mother live as long as possible with comfort and dignity; they promised their father before he died they would. But they've reached the point in their own full lives where their children and grandchildren need their help while their husbands want them to slow down. No one in the family will openly begrudge them the time they give their mother. But the daughters will feel pressure nonetheless to be just as good grandmothers and wives. They also have jobs. Tending Mom will stretch them thin.

Many people add shame to the burden of worry, sadness, anger, and dread over a family member diagnosed with a serious illness as they struggle with ambivalence toward the caregiving task that looms ahead. But it's only natural to feel overwhelmed by the prospect of adding caregiving to an already full plate. Ambivalence toward caregiving should be considered a normal, expectable reaction that doesn't invalidate your love or devotion to your ill family member. It's neither necessary nor helpful to feel ashamed.

They little relish caregiving her for other reasons, too. Their mother was always a take-charge lady who guided them firmly. They know she deserves the benefit of their strength now, but they're leery of flipping the mother-child roles and usurping her power. Telling her which pills to take, when to go to bed, what to tell her doctors—it would all be so presumptuous of them. Who are they to compound the injury of cancer with the insult of condescension? The mere possibility that taking charge themselves might detract from who she's been fills them with guilt.

There's also no guarantee that, once they rearrange their lives to meet her needs, it will end anytime soon. Their father may have succumbed relatively quickly, but they know their tough mother will fight longer. The weeks of driving her may stretch into months, the months of comforting her drag into years. If her cancer progresses and she becomes disabled, they'll have to do even more. Lift her? Change her soiled clothes? Anything's possible. At what point

would they get sick of it? When would they start feeling resentful? Perhaps they'd even pray for her death one day. It seems inconceivable now, but they've heard of other daughters who long provided hands-on care and became just that desperate for relief.

The afternoon drags on interminably. Their mother tries to nap but is unable to. She then tells the older daughter to make several phone calls for her and directs the younger one to track down her nurse to fetch an extra blanket. The sisters are glad for something constructive to do, although they inwardly recoil in the instant their mother orders them about. While it's normal for family caregivers to harbor negative sentiments, the daughters feel abashed by these feelings. They try to squelch them by refocusing on Mom's needs, straightening her bed, fussing with her hair. Some part of them wants to escape home to their waiting spouses. But they feel compelled to stay so that she's not alone with her worries for too long. It strains them to sit idly for hours, watching her in anguish. But they're both cognizant that, because she has a life-threatening disease, every remaining moment with her is time they should cherish. This is only day 1 of caregiving, and the daughters already feel emotionally and physically spent. They fear their mother will need them for days ahead as far as they can see.

Like most family members, these daughters are struggling with the many possible meanings of sacrifice. For some caregivers, giving their lives over to caring for a loved one will gratify them as the most significant, ennobling endeavor they've ever undertaken. Think of Susan Sarandon as the mother in the movie *Lorenzo's Oil* who relinquishes her work, friendships, and nearly her marriage to seek a cure for her son's terminal congenital condition. The mission of saving him becomes the moving force of her being. Other caregivers experience the sacrifices as a form of entrapment or exploitation. Consider Edith Wharton's novella *Ethan Frome*, in which the careworn husband is repulsed by his griping, pain-addled wife and seeks love outside his marriage. By escaping her, he's trying to transform the embittered and lifeless self that caregiving has rendered him.

These dramatic depictions are the extreme poles of a broad spectrum. Few of the close relatives caught up in caring for an ill parent, spouse, or child are as obsessively devoted as a Susan Sarandon or as piteously downtrodden as an Ethan Frome. Caregiving provokes a wide range of emotional reactions to a complicated life choice involving personal sacrifices to yield family benefit. Most caregivers are likely to

experience a mix of emotions about what they do, depending on whether they are reflecting on their lot at any specific instant as individual beings or beholden family members. You may feel proud and angry simultaneously. You may feel angry about being burdened, then feel guilty for having felt anger, and then become angry again for having been made to feel guilty. The combinations are infinite and exhausting. You may find that the tension accompanying your conflicted emotions is a cause of much duress.

In their middle-aged years these sisters have probably known many good people who have taken care of ill loved ones. They may see others' efforts as proof that families have always taken care of their own—that duty wins out over personal excuses and doubts, over work and money, even over all pursuit of happiness. As a consequence, they're likely to castigate themselves for their misgivings and try to shunt them aside. That, however, would do them an injustice. Caregiving has always been hard, no matter how valiantly and heartily some family members have embraced it. As a series of daunting logistical and emotional challenges, it's only becoming more arduous nowadays. For these daughters are embarking on the caregiving journey at a time in the histories of the American medical system and our country's families when there exists a strange paradox: Healthcare professionals have knowledge and technologies at their disposal that make them more self-assured than ever in fighting disease. But the family caregivers of our ill citizens have rarely, if ever, been left so beleaguered.

Several deleterious trends for family members have developed over the past decade. Foremost among them is that increasing numbers of Americans are being asked to set aside some part of their own lives to care for another. According to the National Family Caregivers Association (NFCA), a Washington, DC-based self-help and advocacy group, more than 50 million people in this country provide some care to a relative or friend each year. Of these, about half, or 25 million Americans, the United Hospital Fund of New York City has found, provide ongoing care not just for 1 year but for year after difficult year for seriously ill or disabled family members. In a study by MetLife, the average length of time spent caregiving was 8 years. The largest portion of family caregivers are adult children, like the daughters, who must take care of disabled or demented parents. But increasing percentages also include "well spouses," who tend to ill husbands or wives, as well as parents of chronically ill or disabled children. Regardless of the family role that you play, you're among a steadily growing group of Americans

contending with caregiving's stresses. (This phenomenon is hardly exclusive to the United States: The 2001 census in the United Kingdom reported that 5.2 million family members and friends were providing care for a loved one in England and Wales—a full tenth of the population of those nations.)

The causes of this burgeoning phenomenon are many. Some of it is demographic. As the age of the average American continues to rise thanks to generally improved healthcare, the kinds of chronic, debilitating diseases—such as dementia, diabetes, heart disease, and cancer—that ordinarily develop later in life become more prevalent. According to the 2000 report of the National Center for Health Statistics, over 35 million Americans are encumbered in their daily activities by chronic mental health or physical health conditions. More disease means a greater preponderance of symptoms that diminish the day-to-day functioning of older individuals. More infirm and partially disabled older people create the need for increased assistance from others, namely, family members. For example, when a 75-year-old man with high blood pressure and Type II diabetes suffers a minor stroke that slows his reflexes and blurs his vision, he's no longer able to drive. His son and daughter then have to take turns chauffeuring him to the supermarket twice a week while he, angry about losing his license, carps at them from the backseat about their driving.

Some of the causes are technological. Our age's innumerable medical advances—such as new drugs, improved cardiac, neurological, and vascular surgeries, breakthrough radiological techniques, and leaps in trauma and emergency care—have helped Americans achieve greater lifespans. But living longer doesn't necessarily mean living whole. Rather, technological progress enables people to postpone death but frequently leaves them with impairments that affect their abilities to walk, talk, or take care of themselves. Living longer with functional deficits means spending a larger portion of life dependent on others to help meet their basic needs. For instance, a 6-year-old boy who fell through the ice on a pond is resuscitated at a hospital emergency room and then kept alive by being placed on a ventilator for several days. Without the hospital's sophisticated machines, the child would have perished. But his brain was damaged from oxygen deprivation during his extended period in the water. Years of rehabilitation won't restore to him the prospect of being independent one day. His parents will spend the rest of their days, in the best-case scenario, having to super-

vise him; in the worst case, having to dress and feed and push him in his wheelchair.

Some of the causes are economic. Two decades of efforts to lower healthcare costs have worked toward shifting some of the responsibility for caring for disabled patients from professionals to families. Since acute-care hospital stays are much shorter than a generation ago, patients are discharged home generally sicker, and it's family members who are expected to take care of them. The rapid growth of home-based medical treatments—for example, home dialysis, intravenous infusions, and feeding pumps—call for greater family oversight of procedures that were previously administered only by trained hospital staff. Government programs that provide support groups, case management services, and respite care to caregivers have received better funding in the last several years but still scarcely meet the needs of the vast majority of family members with ill relatives.

A second trend that heightens the difficulties of family caregiving is that families are pulled increasingly in multiple directions. Over the past 30 years, the rise of the two-income family has meant that able-bodied American adults are on the job during working hours and therefore unavailable to be at home to take care of a sick parent, spouse, or child. (The alternative is for one of the well adults to quit working to stay home to caregive. This often means a loss of income for all family members that leaves them financially strapped.) In the past several decades, we've also been a more mobile people, less likely to live in the same town or even the same region as our closest relatives. Consequently, when a loved one becomes ill, family members who care about him the most may be scattered about the country and unable to collaborate closely on a caregiving plan.

This can distort family dynamics. Because members are so widely dispersed, the caregiving burden often falls disproportionately on the relative who lives closest to the patient. Meanwhile, it's common for the family members who live farthest away to voice the most objections to whatever caregiving plan is in place, as if to make up in power of opinion what they lack in proximity. You can be sure that, if you are the caregiver shouldering the brunt of the daily toil, this advice from afar will be not only unwelcome but also infuriating. Especially in situations in which you and your siblings from around the country must discuss a parent's care needs in tense phone conferences or testy family meetings, disagreements about who has the most right to determine

the caregiving plan can cause schisms among you that may last well beyond your parent's death.

A third trend has to do with our prevailing societal ideals. Americans have always valued hard work, independence, and upward mobility. Family caregiving, on the other hand, seems nearly the antithesis of these aspirations. While it entails some of the hardest work any of us will ever undertake, it's about depending on one another, not flying solo, and digging in heels against illness's downward spiral, not climbing socioeconomic ladders. If our culture seems enamored of spending and getting, then caring for an ill loved one is about scrimping and giving. If we take pride in looking out for Number 1, then caregiving practices humility in putting number one last. All of which makes many caregivers feel out of step with American culture at large or simply "out of it"—ignored and undervalued, isolated and disconnected. You may even feel embarrassed or ashamed about what you do, convinced others may view you as practically wasting your life.

For example, the daughters of our mother with cancer will worry that some of their friends won't understand it when they're unable to make lunch dates because of their mother's frequent doctor appointments. They'll be nervous that their husbands, while abiding their attention to Mom, won't appreciate its value or applaud them for it. No one else, it will seem to them, will recognize the magnanimous efforts they make except for their mother—and even she may take the long hours they devote to her for granted.

We're increasingly likely to end up caring for an ill family member, at a time when the task has become more and more difficult for several reasons:

- Caregiving may go on for years, due to longer lifespans and advances in medical technology that leave more adults with debilitating age-related illnesses and other conditions.
- Family members are scattered geographically and have many other obligations (such as work) that compete with caregiving.
- Caregiving runs counter to the American ideals of upward mobility and independence and leaves caregivers feeling out of step and isolated in society.

All these considerations make the sacrifices of caregivers harder to sustain over time. The social systems that could serve as bulwarks for you—cohesive families or responsive healthcare professionals or even a grateful, admiring society—are often absent. It makes the toll for months or years of giving care that much steeper. And the wear and tear on you, caused by the physical and emotional burdens you bear, is already great.

To cite one old but illuminating study, published in the May/June 1989 issue of *Geriatric Nursing*, nursing professor Sandra Gaynor interviewed 87 elderly wives of neurologically impaired husbands about their caregiving experiences. Most of the wives were able to take care of their spouses, with some professional support, with relatively little hardship for the first 2 years. However, as the caregivers approached the 3-year mark, they began to report increased stress. Some had chronic back pain from lifting their husbands. Others had developed chronic sleep problems because of the many nights running that their spouses had awakened them asking for assistance getting to the bathroom or changing soiled sheets and bedclothes. (A 1998 study by the National Family Caregivers Association produced similar results, finding that 51% of the caregivers it surveyed suffered insomnia and 41% had back pain.) By year 4 in the Gaynor study, most of the wives felt unhealthy themselves and were taking prescription medications, such as anti-anxiety drugs. Few took time to safeguard their well-being in other ways.

Two important points arise from these interviews: Taking care of an ill loved one is often manageable in the short term, but the longer care is required, the more damaging is the cumulative effect. Another way of saying this is that most family members can handle a “sprint”—a short period of adrenaline-fueled, impassioned effort—but may lack the stamina to slog through a loved one’s “marathon” illness. Unfortunately, many of the major medical problems that necessitate caregiving, including kidney, liver, and lung diseases, are of the grinding, uphill-and-downhill marathon variety that can sideline caregivers worn down by the course.

Fatigued runners cramp up or tucker out. Tired caregivers tend to burn out or sink. Dozens of research studies have found that family members caring for ill relatives are more prone to developing depression than their same-age peers who aren’t caregiving. The studies cite that anywhere from 6 to 50% of all family caregivers are depressed, de-

pending on whether their authors were counting mere moodiness or full-blown major depressive disorder. The latter is itself a disabling illness that usually entails intense sadness as well as the loss of the ability to enjoy favorite activities, poor sleep and appetite, and feelings of irritability, fatigue, or hopelessness. The approximately 5–10% of family caregivers who slowly descend into this state are often the ones, as Gaynor's interviews suggest, who care for a loved one for long, withering stretches. Other factors also increase your likelihood of becoming debilitated by depression: tending a patient with disruptive behavior or personality changes caused by neurological conditions; having frequent conflict with the healthcare team; and lacking available social and emotional supports. You may simply feel overwhelmed from the outset, maintaining a downcast view of the entire ordeal and of your limitations to handle it.

Whatever combination of factors leads to this state, if you end up severely depressed, you'll have less energy and creativity to bring to your labors. You may become rigid in your care routines, unable to see new possibilities for solving problems or soliciting help. Feeling trapped in an unending nightmare, you end up most vulnerable to eventually giving up. The ill loved one you care for has the greatest chance of one day landing in an extended-care facility or group home.

The second point that can be gleaned from Dr. Gaynor's interviews is that long-term caregiving is not only potentially depressing but consuming. The longer you give your all for a loved one, the less you may seem able to make time for your own needs. Life shrinks down to a narrow focus on getting through the day's feeding, toileting, and pill doling. Self-neglect breeds social isolation when you stop responding to friends' overtures. It's not unusual for caregivers to forgo medical care for themselves, even though they may be visiting doctors weekly with an ill loved one. This puts you at risk for unwittingly sacrificing your own physical health. Even if you go to your own doctor, caregiving may negatively impact your well-being. A 1999 *Journal of the American Medical Association* article reported that elderly caregiving spouses who had their own chronic illnesses were 63% more likely to die than their noncaregiving peers. A 2003 *Proceedings of the National Academy of Science* article found that family caregiving can compromise your immune system. The danger is clear: If you should break down before the relative you care for, both of you may wind up needing help from others.

The daughters aren't aware of these possible extremes. In the first days, like most family members, they feel only a vague apprehension of what's to come.

Shortly before the dinner tray arrives, a short, gray-haired social worker bustles into the hospital room. She announces that the mother's abdominal surgery to remove the mass will be scheduled in a few days and that she'll go home in the meantime. Neither the doctor this morning nor the nurses who had popped in during the day had mentioned anything about the discharge. The mother says, "All right. It will be good to get home, even for a little while." But the daughters just stare. As impatient as they are to get out of the hospital, the thought that their mother will soon be back in her small apartment makes them nervous. "Why isn't the surgery being done right away?" the older one asks. The social worker responds, "I don't know. It's the doctor's decision." When the older daughter's flustered expression remains unchanged, the social worker adds: "Cancer patients seem to do better when they're in their own homes surrounded by the people who care about them most. I'm sure she'll handle the surgery better after resting at home first."

She turns toward the mother again and says: "Your doctor will discuss the plan for the upcoming surgery and subsequent treatments with you when he gives you your discharge papers. Here's a list of home health agencies if you want to hire extra help to assist you with bathing, dressing, or maybe cleaning. I also have this patient education manual called *Coping with Cancer*." The older daughter interjects again, "What subsequent treatments are we talking about?" The social worker answers, "It's not my place to guess. The doctor will discuss it all with you." Both daughters frown. The arrangements seem haphazard and disjointed. The mother thanks her for coming. As the social worker reaches the door on her way out, she turns and asks the daughters if they have a few minutes to talk with her in the hall.

Despite the hurry she's in to meet with other patients, the social worker wants to communicate to these daughters that she understands what they're feeling. She has seen many families struggle with medical crises; she knows serious illness happens to families, not just individuals. She also knows that how family members fare is crucial to the medical outcome of the patient. It's not only that families drive patients to the appointments and badger them to follow the regimens of pills, diets, and exercises that physicians order with a flourish of pen on prescription pad. It's the intangibles that family

members supply—the encouragement and humor, happy memories and favorite stories, love and a sense of purpose—that can make the difference between the ill person who sustains morale and the one who slips into pessimism. When daughters become demoralized, their mothers lose some fighting spirit. Without the patient's fighting spirit, medicine is hamstrung.

The daughters lean against the hallway railing once again. The social worker tells them empathetically she knows how hard these situations are for family members. She gives them her business card and says they can call her at any time if they have any questions about social services. She mentions the upcoming monthly meeting of the hospital's support group for the relatives of cancer patients. The daughters are just beginning to feel more relaxed with her when she adds, "If you're really worried about how your mother will do in her own residence, maybe one of you can take her into your home for a little while." They each look at her, suddenly befuddled, and say nothing for several moments. Neither of them particularly wants to have a conversation with her husband about bringing their mother home with them, though they know they should. They expect it of themselves. And they don't need to be prompted by a professional who barely knows them. The older sister finally responds in a flat voice that sounds indifferent, "We'll have to talk about it among ourselves." The social worker looks at them askance as if doubting they'll talk about it at all. Perhaps they won't follow any of her other suggestions either. She quickly wishes them luck and hurries down the hallway to meet with another patient and family.

They say nothing to their mother about the social worker's comments when they go back into the room. Mom's appetite has finally returned, and she's picking at the salad and roast potatoes on her tray. Seeing her eating gives them some reassurance that she's starting to recover from the morning's shock; it also reminds them of their promises to be home for dinner with their spouses. "We have to go. We'll be back in the morning," the older one says and bends down to hug her mother. They linger for a few minutes longer, fidgeting with the blankets, before finally shuffling out the door.

In the elevator on the way to the garage, the younger daughter says, "The social worker meant well." Her sister retorts sharply: "Everybody means well. They're full of advice and suggestions before they go running out. But she's our mother, and they expect us to make sacrifices for her." Later, as they enter the garage, the older sister says in a softer tone: "It's up to us to take care of her. Let's talk in the morning

about whether we need to take her home with us. We'll take turns if we have to." The older daughter gives her sister a warm tap on the upper arm. Then the two of them climb slowly into their cars.

They drive home feeling even more greatly burdened than they did the night before. They have no intention of shirking their duties. They just want to handle them well and are not sure how.

There are tasks that the sisters will need to master to care for their mother as effectively as possible. They'll have to figure out what commitment they're willing to make to caregiving for now and then review that commitment periodically as time goes on and circumstances shift. They'll need to take advantage of all the support they can get, even if they don't think they need it and don't believe it will ease the "real" burden of taking care of their mother. They'll have to find the tenuous balance between sacrificing enough and sacrificing too much. As their mother's illness runs its course, they'll need to achieve another balance too—between hope and acceptance about what they can expect. To maintain that balance they'll need to stay aware of what's happening to everyone in the family so they can respond flexibly to changing needs. And in the midst of all of these travails, they'll have to guard against the dehumanizing loss of intimacy between themselves and the mother they love and also between themselves and their own spouses and children. Finally, they'll have to find ways to sustain the spirit by ascribing some greater meaning to this painful passage in the family's life. There's no exact order for accomplishing these tasks, but all should be thought through at some point during the caregiving ordeal. In the following chapters, we'll discuss each one, along with the challenges it poses for these daughters.

Before you can successfully undertake any of the subsequent tasks, however, you'll need to consider your level of commitment. What do you want to do? What are you realistically capable of doing? These are questions you'll probably answer differently at different times through the course of a loved one's illness. What level of commitment can you sustain for as long as the patient needs you—possibly years? Caregivers notoriously overcommit themselves and then feel trapped by promises they've made that slowly break them. Chapter 2 explores these and other questions to help you think through what you're willing and able to do so that you're comfortable with the commitments you make.

Limited Mobility Leads to Wounded Pride

Q: *My mother's arthritis has made her less and less mobile, so my family has been doing more and more of her chores and errands for her, from cleaning house to grocery shopping. This has been pretty easy to organize, and we've been able to joke her out of feeling humiliated by her dependence on us. But now her memory is really starting to go too, and she has written checks that she's forgotten to enter in her checkbook or forgotten to pay bills altogether. We know we need to start helping her with her finances, but she's very proud of having been able to take care of this since my father died. I could try to take over some of it without her being completely aware, like having some of her bills paid automatically online, but that seems so condescending I'm not sure I can pull it off. How can I broach this subject without making her feel ashamed?*

A: The fact that you're so sensitive toward your mother's feelings is in and of itself the most important factor in helping preserve her dignity as well as possible. There are other issues and strategies to consider, though, to promote this worthy goal through raising conscious awareness and choice.

A first step is clarifying her medical situation to help you better determine what aid she needs now and will in the future. The key question to pose to her physician is whether her conditions are chronic and progressive; if so, she undoubtedly will require even more of your help over time. You mentioned two separate medical problems: Osteoarthritis is generally chronic and progressive, but the degree of impairment it causes varies from one person to the next. I'd ask her physician if pain-reducing medicines and other interventions are likely to roughly preserve your mom's physical capabilities or whether she's likely to lose the ease of most of her movements. Her other condition—whose symptoms include short-term memory deficits and difficulties with concentration—is more vague. Is she suffering from early Alzheimer's dementia (chronic, progressive, and ultimately devastating), multi-infarct dementia from small strokes (whose resulting deficits may get no worse if further strokes can be prevented), or possibly major depression (whose symptoms are reversible)? Since cognitive impairment typically impacts family caregivers more than physical disability, asking her doctor to make a specific diagnosis is crucial to helping you plan ahead.

A second step may be counterintuitive: Don't shield your mother from the diagnoses and prognoses her physician makes. Trying to protect her from unwelcome news about herself that would hurt her pride would itself be infantilizing. Simply on the basis of medical ethics, your mother has the right to be fully informed about what she'll likely face. Such disclosure also has psychological utility: She'll have the information to grieve what she's losing and prepare herself for the increasing infirmity—and possible dotage—that will change her. She'll then be in a position to deliberately decide on the kind of assistance she wants now and in the future to deal with these eventualities.

Once steps one and two are completed, the third step will come much more easily: Have a discussion with her about the role she wants you and your family to play with her over time. Tell her you want to face her decline together as a family. Point out the accommodations you're already making for her and that you're prepared to do much more. Then let her guide you as to what she wants; given the circumstances, that's the best way to help her keep her dignity. If she unrealistically declines your help, saying she won't need it, gently remind her of what the doctor said. On the other hand, if she opts to go into a nursing home rather than burden you and your family, you may try to talk her out of it but should ultimately respect her right to decide how to live out the rest of her life.

How does all this translate into helping her day to day? You're already attempting to allow your mother to do as much for herself as possible. I'm sure you'll continue to strike the balance between helping her save face and helping her remain safe; you'll likely err on the side of not aiding her any more than you absolutely have to. But there still will be instances—for example, paying bills—when you'll need to confront her about her decreasing capabilities. That isn't a matter of shaming her but of gently priming her adaptation to new realities. The common medical understanding you and she will have gained may make those moments somewhat easier, but your mother will still feel mournful at those times. That's a natural response, one you shouldn't try to stop her from having. That's her best emotional means of coming to terms with the vicissitudes of age and fate.

The Guilt of the Long-Distance Caregiver

Q: My sister has been serving as my father's part-time caregiver in a town about 2,000 miles away from me. Since I'm not there, all I can do is

act as an emotional support and try to provide practical advice as well. We have different ways of coping with my father's infirmity, but we've managed to work together on all decisions regarding his care. I have been feeling the guilt of the long-distance caregiver while simultaneously being emotionally drained from supporting my sister. My father seems to need more and more care every day. My sister seems overwhelmed, and I'm frustrated that more is not being done. Short of making repeated trips cross country, what can I do to ensure my dad is truly getting the care he needs?

A: The long-distance caregiver is frequently a controversial figure in family circles. While she invariably means well, she's often maligned by the on-site caregivers for several reasons. She's told she has no business trying to throw her weight around from afar because she's not close enough to the situation to really understand it. When she says in her own defense she has a job and/or family that keeps her at a distance, she's told she should never have moved away. If she becomes so frustrated by these criticisms that she decides to turn her back on caregiving by not coming home or calling regularly, she's then lambasted for abandoning her parent and siblings.

As unfair as this all seems, there are probably some germs of truth to these criticisms. Long-distance caregivers are sometimes the offspring who, years before, moved far away to escape their families of origin. When aging parents become seriously ill, they do have a tendency to charge on to the scene out of nowhere like self-styled marines hitting the beach. If they decline providing care with the rationales they're too far and too busy, siblings rightfully feel abandoned and angry. Yet, long-distance caregivers have a distinct advantage that gives them an important role to play in a family's overall caregiving plan: Their distance allows them to see the forest for the trees when those closer to the scene are too focused on the wood-grained detail of every caregiving task to perceive how the family as a whole is managing.

It is on the basis of your more distant perspective that I'd reach out to your sister. I'd call her or, better yet, fly home specifically to meet with her in order to relate what you're seeing from your 2,000-mile vantage point. After telling her how dedicated and loving a caregiving job she's doing, broach your concerns about how father's decline is affecting your sister's well-being. If she responds by saying you aren't there every day and therefore don't understand, tell her that not being there every day may actually help you more readily see the incremental changes that are slowly occurring. If she argues that your father isn't as bad as you con-

tend, cite instances of how Dad has changed from one of your visits to the next—even if your sibling has been unaware of these changes. If your sister counters that she herself isn't struggling nearly as much as you imply, offer observations of how burnt out she sounds on the phone and appears during your infrequent visits. Above all else, tell her you love her and your father and want to do your utmost to help them, including getting your dad more help in his home or considering other living arrangements.

Keep in mind that this discussion will likely need to be repeated in subsequent conversations before your sister will trust what you're saying and embrace getting more help. Your credibility as a concerned, far-sighted long-distance caregiver will depend on how well you convey that they're always close in your thoughts. Call and visit as often as feasible.