



## Chapter 6: Know What to Expect

Whether you have formed a care-share team for yourself or for someone else—or even if you’re just contemplating whether or not to join a team—you can realistically assume that there will be surprises ahead. When you’re part of someone’s personal safety net, try to plan as best you can, but prepare for the unexpected. You may find yourself protecting the care partner’s privacy, feeling intense emotions, fighting stress and burnout, or simply wanting more time for yourself.

### Loss of Privacy

It’s always hard to give up or share privacy. As a potential caregiver, you can be very sensitive and respectful of the care partner’s personal space. Keep in mind that the care partner’s privacy needs may ebb and flow based on treatments, fluctuating feelings of vulnerability, and other factors.

#### Catherine Protects Benjamin’s Privacy

*Catherine knew she needed help caring for her husband of sixty-two years. She and her husband enjoyed strong bonds with several close friends, including their next-door neighbor, Alice. Both friends and neighbors were eager to help this wonderful couple as soon as they heard of the need, but Catherine was worried that their help might compromise Benjamin’s needs for privacy. Benjamin was a retired physician and Catherine a wonderful musician. They were cultured, proper, and well mannered in the style of the country from which they had immigrated.*

*Benjamin had suffered a major stroke. Although he had completed nine months of rehabilitation, he had not recovered his ability to speak or use one arm and one leg. He needed help with many personal tasks.*

*As days passed and Catherine came to acknowledge how tired she’d become, she finally agreed to let their neighbor, Alice, help. Alice was a gifted and sensitive physical therapist and knew to treat Benjamin with the utmost respect, to always maintain his personal modesty in even the smallest of ways, and to express what an honor it was to give back to a man who had given so much to so many people. Catherine could tell that Benjamin liked Alice and was able to accept her careful entry into his personal and private space. With time Catherine and Alice brought, one by one, more friends to join in a care-share team. Catherine thanked Alice for her sensitivity and “way” with Benjamin. Alice talked with each new team member about what she had learned in helping Benjamin be comfortable receiving help. Most importantly, Benjamin’s life was enhanced by increased, sensitive interactions.*

It’s often difficult to figure out how to speak sensitively and act respectfully once privacy needs are known. At issue may be the care partner’s physical needs (such as speaking on the phone without being overheard, or bathing) or emotional needs (knowing the details of her life won’t be shared with anyone else). Even if the care partner is unable to talk about such issues, team members can help one another.

### Difficult Feelings for Everyone

One of the more challenging and, at times, rewarding aspects of sharing care involves dealing with the various and sometimes new feelings you may experience. Often, in times of crisis or great stress, people act out of fear. A friend tells this story about Brigitte, suggesting that her fears guided her actions.

#### Brigitte’s Story

*My friend Brigitte didn’t tell me she was being admitted into the hospital. Though she had once talked about creating a list of who was helping her, this never happened, and I don’t think many of her friends had actually met each other. After days of worry, I finally found out that she was in the hospital, so I went to see her. I told her that I*



*had felt worried and alone when I didn't know where she was. Brigitte, in turn, admitted her fear that if those involved in assisting her knew one another, they'd bond together and leave her. I replied that it was more likely that we'd support one another in helping her. But she was unconvinced.*

You may dismiss Brigitte's extreme fear and think, "I wouldn't have that fear." However, being a sensitive member of a care-share team requires tuning in to the unique person whose life has now changed and who is trying to find stability in this foreign and often frightening territory of change or illness. If you are caring for a relative or close friend, you may feel you know that person well and know what to expect. But this is not always true. Adopting a curious, open, and accepting attitude toward how a friend or loved one will respond in this new territory can be very valuable.

The following is a partial list of some of the commonly reported feelings that we two authors in our various professional and personal experiences have witnessed or personally felt. When reading this list try to imagine what it would be like to have this feeling. Do not judge it, but rather experience it. This will help you prepare for a time when this feeling may arise in you or another team member. If it is you who is the care partner, then take comfort in knowing that others have felt exactly how you feel.

### Intense Emotions

- **Numbness/Denial:** "I can't believe this happened to me"; not wanting this to be real; seeing a small improvement as major hope; thinking "I'll get well."
- **Fear:** "I can't do this," or "I don't know what to expect."
- **Suspense:** "When will I get well?" or "When will I die?" or "When will I hear the things I've always wanted to hear?"
- **Anger:** at the illness, at siblings for not helping more, at watching money dwindle, at feeling helpless, at the disruption in life, at the unfairness.
- **Guilt:** for feeling anger, for not doing more, for not taking better care of myself, for burdening others, for being sick, for needing help, for not being able to bear or alleviate the pain, indignity, or humiliation.
- **Compassion:** for both myself and others, as we cope with needs, pain, impatience, or grief.
- **Grief and sadness:** for dreams that may never come true, for relationships that will never be the same, for missed opportunities, for a future that now seems shorter.
- **Regret:** for what wasn't said, for time not taken, for dreams not realized.
- **Shame:** for wishing to die, for not always saying thanks, for not always giving wonderful loving care, for getting sick in the first place.
- **Embarrassment:** for my appearance or behavior, for not having it all together.
- **Joy:** for all that my life has meant or brought to others, for small tokens of love or affection, for seeing an end to the suffering and exhaustion.
- **Powerlessness:** nothing will make a difference, not being able to bring comfort, not being able to "solve this problem," not being able to do and give in the old ways.
- **Burnout:** for too many demands, too few breaks, too little coming into one's life, the medical demands.
- **Protectiveness:** of our loved one, of ourselves, of our ideas, of how things ought to be.
- **Laughter:** Sometimes the tremendous stress and tension can be relieved through humor. It's wonderful! Don't be embarrassed or shy about it or the intensity with which you laugh. You need it, too!
- **Confusion:** in the face of any or all of the above, often intensified by fatigue and feeling overwhelmed.

This may be a time to take a break from reading this book. Many people find the "emotional rehearsal" of trying on these various feelings very tiring. It is hard work, but may leave you better prepared for the emotional demands of caregiving or care receiving. It is helpful if you can talk with others along the way. It's comforting to know you are in the company of others who care. In the following story, a sensitive man reflects back on the conflicted emotions he experienced as a young man who helped care for his mother.

### A Family Reacts to Nellie's Stroke

*It was 1967. I distinctly remember sitting in a booth at the small country cafe where our family was well known. It had been over two years since Mom's massive stroke, and there had been little recovery. One aftermath of her*



*stroke was that she could not eat without spilling food all over herself. The stroke also left her with the strange quality of starting a sentence but then skipping from topic to topic without stopping. Whoever she was talking with was then held captive for long periods of time. My sister was then eighteen, I was twenty, and Dad was forty-three. As much as we all loved Mom, we were also wrestling with our feelings. We felt protective of Mom, but we also felt embarrassed: She had taught us impeccable table manners that she herself could no longer follow. We struggled with powerlessness to make it all better despite all our efforts, prayers, and conversations with health-care professionals. We felt anger that things were so different compared to before Mom's stroke. Tenderness, love, and compassion were there as well as we sat with this innocent and vulnerable person, our mom, who now relied on us for her care and well-being.*

Delving into the many ways you can come to grips with feelings as a care partner or as a caregiver is beyond the scope and intention of this book. Yet you must recognize and manage feelings and reactions. Many people find help through friends, family, clergy, or support groups, and others choose to consult with a counselor specially trained in this area. Many books in the Bibliography offer excellent guidance. We encourage you to talk, read, consult, pray, or process in as many ways that make sense to you.

Far too many husbands, wives, adult children, partners, and occasionally friends, out of love and responsibility, provide more care than they can physically and emotionally sustain. This often happens because they have not created a safety net and are used to being very self-reliant and independent. Or it happens because they think of their loved one as the only person needing help. But this can be heartbreaking to watch. We've seen well-meaning loved ones jeopardize their own health, sometimes even their own lives, by putting another's needs so exclusively ahead of their own. This usually happens slowly, until one day, a caregiver burns out, experiences a health crisis, or uncharacteristically loses his temper and lashes out at the care partner. Remember how Catherine, in this chapter's first story, recognized her need for help in time? Beth, in the story below, takes longer.

### **Beth's Story**

*Beth was fifty-nine. She lovingly cared for her seventy-eight-year-old husband, Harry, whose Alzheimer's disease had progressed to the point where he could no longer remember his age. He became confused and agitated in the late afternoon, insisting on going for a walk and feeling upset when he couldn't remember where he was. His twenty-three-year-old daughter regularly stopped by so Beth could run errands and shop. Eventually Harry began waking in the night, going outside, and heading off. Beth, exhausted and frail, had lost weight, neglected her health, and feared she might be developing even higher blood pressure. She was too busy to go see her own physician. During one especially frightening night, Harry walked off and could not be found until early morning when the police brought him home. There they found Beth on the floor. She had suffered a stroke.*

Beth's dramatic story is all too common. It underscores the critical need for care teams to support *all* members so that no one single person carries too heavy a load. Also, care sharing allows the primary loved ones—whether spouse, son or daughter, partner, or friend—to rest, take good care of themselves, and maintain connection with the rest of their lives. They then have much more to give during the time they are with their loved one.

### **Burnout**

Recognizing and setting personal boundaries is one helpful way to avoid getting overwhelmed or experiencing burnout, which is feeling empty and having nothing left to give. To help your care partner maintain the best quality of life possible, it's important to sustain the good function of yourself and your team. Primary or solitary caregivers are notoriously overworked, under-recognized, under-supported, isolated, and likely to suffer from burnout. But team members, too, can become overtaxed. While good communication, well-thought-out care plans, and many outside resources can help stave off burnout, only you can prevent it. It is important to learn to recognize the signs of burnout—both in yourself and in the other team members—and take a break, when needed.

Burnout refers to feeling as though there is “nothing left to give”—emotionally, physically, mentally, spiritually, or all of the above. The well is empty. Stress contributes to burnout. So do environmental factors, such as working conditions, home life, or health. Burnout generally occurs over time, although the related symptoms may seem to occur overnight.



People experience burnout in varying degrees of intensity and duration: Some feel a lack of energy. Some wish to escape entirely. Some constantly struggle with the effects of burnout. As a caregiver's struggle continues, burnout threatens physical, mental, and emotional health. You can recognize the signs of burnout and take corrective action before it is too late. We have compiled the list below to help you recognize these signs and prevent you from being drawn into this state, which jeopardizes your health and your ability to offer care.

### Symptoms of Burnout

- I no longer participate in the activities I used to enjoy.
- I feel blue, irritable, hopeless, and helpless more often than not.
- I find myself getting upset more quickly than normal.
- I am getting sick more often than normal.
- I feel like I can't take it one more day.
- I feel overwhelmed and fantasize about escape.
- I want to hurt the person I am caring for.
- I want to hurt myself.
- I have a low frustration tolerance.
- I feel futile, and at a loss for meaning and purpose.
- I feel emotionally exhausted and spiritually bankrupt.
- I feel depressed.
- I am being more moody than usual.
- I have less patience.
- I am emotionally withdrawing and having fewer contacts with friends.
- I am experiencing more difficulty sleeping.
- I worry more.
- I am expressing a more negative attitude than usual.
- I feel more apathetic.
- I feel more cynical.
- I feel overwhelmed.
- I want to distance myself from the team.

If you're feeling burnt out, you may find it helpful to consult with a professional counselor who specializes in the unique stresses and strains that go with caregiving. Or you could use the following list to help you stop or slow your growing burnout:

- Are your expectations of what you can do realistic? Do you need to shift them?
- Do you need to get better at saying no and at setting limits to protect yourself, your time, your energy?
- Do you need to know more about the illness, disease, surgery, and situation?
- Can you ask for help? Remember *help appeal* and practice asking for help. In workshops we often practice asking for help because it's so foreign and so hard for many of us.
- Would you benefit from developing and using both your team and your personal safety net?
- Are you taking breaks? The sooner the better. Many caregivers complain that it's a hassle to arrange substitute care. We suggest you make taking breaks part of your routine; you can build your "days off" right into the schedule, and other members can learn to cover for you.
- Is it time to learn a stress management technique? Find a great book, audiobook, or workshop. Pick one, learn it, use it, and it will help keep you healthy and de-stressed in all aspects of your life.
- Call a counselor or consultant who is an expert on what you're experiencing.

Jody, in the next story, turns to a professional care manager when she's at her wit's end. Her story is told from the care manager's perspective. It holds out hope for those of you who are exhausted.

### Jody: Care Plan for the Caregiver

*Jody had wanted to consult with me about her forty-six-year-old husband whose battle with cancer was in its*

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*second year. He had become increasingly withdrawn and emotionally closed off. She and their late-adolescent children were concerned and missed his personality and emotional presence. They'd heard that I could be helpful to men dealing with serious illness. While, as a counselor and coach, I believed I could help him recover some emotional solid footing, my first concern was Jody.*

*She looked and sounded exhausted. While she was telling me about her husband, his illness, his treatments, and how hard all of this had been for him, I was able to extract some information about her. After assuring her that I would meet with her husband, I turned my attention to her. She had many of the symptoms of burnout, and she confessed to not having seen her own doctor and dentist for her annual check-ups and to numerous other examples of self-neglect.*

*Our time had run out and I agreed to meet with her husband on one condition: that together we develop two related plans. One plan would be for her, to help her regain her health and reduce her load. A second plan would be for a care-share team, which would be valuable both to her husband and to the rest of the family. She trusted me, we met, and we created both plans. With many modifications over the next several months, our plans supported the family to the end of their difficult journey.*

### Needing Time for Yourself

Part of Jody's care plan for herself was establishing her own boundaries or limits. Besides sharing the concerns and care for her husband with a team, she also learned to take time for herself.

### Lorraine's Tale

*Lorraine had always been the beautiful belle around whom all the others flocked. She was always ready for a party or an adventure. Tim fell madly in love with her, paying no attention at all when she told him of her progressive disease that would probably claim her life early. What could that matter to him when he loved her so much?*

*Years went by, and the disease did make inroads. Lorraine's ability to move about dwindled alarmingly. Pain became her constant companion. She was forced to follow a complicated medication schedule. Tim was Lorraine's main caregiver, yet he was also holding down a job—and feeling more and more overwhelmed. Even when they hired caregivers for daytime help, Tim's evenings were always slated to care for Lorraine.*

*Tim didn't mind at first. He gladly did what was needed. As time went on, however, and the bubbly and competent woman he'd married became bedridden and pain filled, Tim's own inner resources were stretched thin. He didn't see how he could get any relief and became resentful. Yet being angry seemed wrong to him somehow, when Lorraine was so ill. Concerned friends offered to help, but Tim declined.*

*One night, Tim just didn't come home. On another night he "went for a drive" and drove to the next state, not returning until the wee hours. On a third night, he took Lorraine with him, but left her medicines behind. Tim was acting out his frustrations and feelings in a way that really endangered Lorraine.*

*For her part, Lorraine covered for Tim. She told caregivers who arrived in the morning that she'd just overslept and that was why she'd not been to the bathroom. Doctors questioned whether Lorraine was taking the proper dosages of prescribed medications after their effectiveness decreased. Finally, someone reached the conclusion that Tim needed help, too.*

*Unfortunately, by the time Tim received this offer of assistance, his relationship with Lorraine was beyond repair. The trust had been broken irrevocably. It would have been so much better if Tim had invited others to help him care for his wife sooner. Though neighbors and friends had offered, he hadn't acknowledged his own inadequacies and therefore was unable to accept help. In trying to go it alone, he put Lorraine in danger, as well.*

*When the group stepped in to help, Lorraine stopped denying her need. Tim, ashamed and frustrated, left the house. Although their confusing scenario ended in divorce, in the end Lorraine received better care and lived for many more years.*



Like Tim, many people only learn the hard way to know and respect individual limits. Then it can be too late. Asking for and accepting help before there's a crisis is a huge favor for all involved. In the next story Gary seeks help just in time.

### Gary's Final Straw

*Phyllis had been disabled for many years by a massive stroke and then congestive heart failure. Gary, her seventy-year-old husband, was exhausted and burnt out by the combination of caregiving and operating his farm. For several years his doctor had been insisting that Gary take some time off, but he just didn't see how he could. A source of strength for Gary was a close friend, Phil, who was also caring for his own wife. While they loved their wives, the strain of solo caregiving had gotten to be too much. Gary and Phil both imagined a time when their loved ones would pass on and they could retire with time and energy for some pleasurable activities with other family and friends. Then Gary's friend unexpectedly died of a heart attack. Gary was grief stricken and brought to his knees by both the loss of his friend and the shattering of his dream and hope for shared time later.*

*Only when Gary became seriously depressed did he ask for help from others, who came together as a care-share team. A niece, who was director of nursing at a nearby nursing home, arranged temporary care for Phyllis. Gary took a long overdue vacation to Florida to walk the beaches, nap in the sun, and visit with relatives there. For the first time in years, he relaxed, free of pressures and responsibilities. Two weeks later Gary returned, rested, healed, and ready to resume his responsibilities for the remaining seven months of his wife's life. For these months, however, both he and his wife were supported by his niece, family, and friends.*

As a caregiver you may be so busy performing daily tasks that you forget to check in with yourself and assess your emotional, physical, and spiritual well-being. As hard as it may sound, setting aside some time each day to sit in a quiet place and turn attention inward can help charge your care-giving batteries.

Some people meditate during this time. Others take a walk or retreat to a special place in the home or a favorite cafe or park bench where they feel at peace. Exercise is another powerful antidote. Whether you take half an hour or half a day off from caregiving responsibilities, the time should help clear both your mind and your spirit.

Spend a few moments assessing your situation and honestly determining if it is time to seek more support. Be realistic: It takes a whole community to support a care partner—that is what the care-share team is created to do. Don't worry yet about how or where help will come from. What's important now is taking even small signs of emotional distress seriously. It's best to address the problems before they develop into a crisis.

Once you've arranged for extra help in caregiving, you will find that you have time to focus on other interests. It is critical to have activities in your life that renew you and leave you with added vigor and energy. These vary from person to person, of course, but it's important for you to discover what renews you and pursue it. It is important for you as well as your care partner.

With adequate care support, you'll also have time for other important relationships in your life. All relationships require attention, and because caregiving can be incredibly time consuming, often the entire family suffers the loss of the primary caregiver's focus and energy. Friendships will have lapsed as well. Reaffirming other relationships can have wonderful, revitalizing results—and will actually enhance caregiving abilities. By involving a care-share team, the members can help one another remember their individual needs for boundaries, balance, and self-care.

### Life as a Medical Problem

With a serious or life-threatening illness, your life may seem to be primarily a medical problem. How will this affect my ability to visit my children or grandchildren? Can I go to work? Can I get to the grocery store? Can I watch TV? Will my retirement be what we had hoped and saved to make it? This perspective is often colored when you're undergoing a medical test. What will the test show? What happens if it is positive? When waiting for medical test results, which can take days and days, you may simply put your life on hold; you're unable to focus on anything else.



You may worry that, from the outside, this looks terribly self-absorbed and even selfish. But you also know, inside, you are facing fears and uncertainties, and your mind and attention are being taken over by the illness. Both push what used to be “normal” away and often increase your sense of isolation from close family and friends.

### Tina’s World Got Smaller and “Medicalized”

*Tina’s world began to shrink as her disease process continued. More and more of her time and energy became focused on doctor’s appointments, visits from home-health nurses, and the difficulty of performing simple tasks. Fewer and fewer things outside of this immediate realm interested her. Most of the people Tina interacted with wanted to know about her health. Her energy level seldom could be sustained beyond responding to their queries. “How are you feeling?” replaced “What do you think about that guy who was elected to our school board?”*

*Tina’s close friends and family would probably not admit it, but their image of Tina was shifting from mother, sister, and friend to “the sick one.” The shift eliminated any common ground needed for relationships to flourish. People drifted away, and Tina felt more isolated.*

*Then Tina broke her ankle. Because of all the stairs in her home, she needed to recover in a rehabilitation facility. This intensified not only the focus on health and healing but also Tina’s “medicalization.” She became a “good” patient: She presented more symptoms, more problems. She was “interesting” to the doctors and nurses, who regularly checked on their “poor” patient. The attention increased with more need, and to a certain extent was appropriate and good.*

*Fewer and fewer people came to visit Tina. And as her mobility declined, her weight increased. Eventually her ankle healed and she returned home, but moving about became even more difficult. She needed more help with her care than ever, and moving to a nursing facility seemed to be the next logical step.*

*During her stay in the nursing facility, Tina’s symptoms multiplied and she saw fewer and fewer visitors. Outside circumstances required Tina to move yet again, and her situation was beginning to seem hopeless. That’s when a skilled therapist entered her life. With newfound vision, will, and hope, and the guidance of her therapist, Tina chose to move into a hybrid assisted living/boarding house. Family and caregivers couldn’t imagine what would become of her.*

*What happened next, however, was a testimony to Tina’s inner strength. In a setting with more real-life activities and a broader spectrum of people about her, Tina’s self-image improved. She slowly shifted her focus away from her symptoms and toward the needs of the other residents—especially to newcomers. While she did not return to full health, she did begin to make new friends and become more interested in others, and, in turn, more interesting. Her “medicalization” appeared to be in remission. Perhaps it would not return.*

An illness means a new set of characters will enter your life. In one respect, you may view these doctors, nurses, and insurance representatives as unwelcome intruders. You may just wish they would all go away. In another respect, however, these new folks are the people who will help you heal and enter this new phase of life. Each of them is a gift. They provide understanding and knowledge, deliver needed treatments, and may notice small but significant changes that will help you cope. And while their roles are important, they may not understand or be able to deal with all the emotional issues involved. It’s wise to try to prepare for this. They react with their own hopes, fears, preferences, and opinions, which may or may not be compatible with yours.

### Lack of Stability

You may question how to respond to these new people who have now taken such important roles in your life. Your first reaction may be to dismiss them. Another reaction is to comply unquestioningly to their directions, but this can make things even worse. Those patients who often fare the best are those who see themselves as in charge of their own health and who view their physicians as critical team members. Being feisty, making personal decisions with a lot of input, and not necessarily pleasing everyone seem to be life giving and health promoting. These



characteristics help you take control and thereby decrease your anxiety. Even small steps matter. It is often through first experiencing and then dealing with emotional reactions that you develop your emotional solid footing.

It is okay to question, get angry, and fight for life. With questioning comes understanding, with fight comes hope. It is important to question repeatedly, especially if frightened, anxious, or in pain. Repetition reinforces your understanding and helps you achieve the solid ground necessary for further discussions and treatments. Smart patients make conscious and repeated efforts to develop and use all inner and outer resources to find and re-find stability in this new world.

### Wendall's Search for Emotional Stability

*First the symptoms, then the many doctors' visits and tests. It was all exhausting and frightening for Wendall. Having been through a lot of unexpected and unwelcome changes in his fifty-seven years, he believed himself to be quite resilient. Yet the diagnosis of an incurable cancer was way beyond his worst fear. Using all his knowledge, and that of many wise friends, he was able to minimize some fears, manage others, and continue many of his normal activities during the first few months. Some of his tactics to gain emotional stability included talking with his family and close friends, learning about his illness, and arranging for good medical care. He learned about alternative complementary health care, spent time in prayer, found solace and inspiration from others who had faced what he was now facing, and sought wisdom from caring counselors and consultants. Even with the intentional use of these strategies, and many more, Wendall still at times felt out of control, as if he was standing on shifting sand. Wendall realized that finding and re-finding stability amid these uncertainties would continuously challenge him. He often reminded himself that he was building a "road map" for what was ahead. He had met and survived many challenges in his life thus far and trusted he would face and meet this one, too.*

### Judgments about Illness

Serious or life-threatening illness can easily become public knowledge. Who can ignore in our neighbors or friends the visible signs of illness? Bandages, hair loss, crutches, and wheelchairs are clues to everyone that something is amiss. We are naturally curious to know what has happened. Even if the illness is not obvious, it often is known to our relatives and friends and subsequently many others in our lives. Who knows and doesn't know is often beyond our control.

Each person who finds out about someone's illness deals with it uniquely. Once a family member, friend, or colleague hears of an illness, questions arise: How did this happen? What does it mean for my friend? What does it mean for me? Why did this happen? There are a host of implications the illness might have on a relationship.

What happens to the information once it's shared is interesting, too. People's reactions depend as much on the meaning or beliefs they hold about the nature and cause of illness as it depends on what they're actually told, when they're told, or by whom.

In his book *Grace and Grit*, Ken Wilber describes attitudes held by many major religions toward illness. Regardless of beliefs, it is clear that perceptions of the cause of the problem can vary greatly even among friends and relatives. Understanding others' beliefs may help in tailoring responses to the problem and possible solutions. Mutual respect and appreciation of differing perspectives is often called for in a care-share team setting.

### Loss of Perspective

Finding, losing, and regaining perspective is an ongoing challenge whether you're giving or receiving care. And one of the deepest sources of pain for caregivers is guilt: "I promised him that I would never put him in a nursing home." "I promised him I'd protect his privacy by hiding his disability." "If I don't come by for at least two meals I can't be sure they'll feed him." "If I don't move in, he'll be sad, and then I'll feel guilty." "If I don't bail her out financially, her business will fail." Even when you really love the person you're caring for, the well from which you are attempting to draw can be filled with frustration, guilt, and occasionally anger at a situation that may seem entirely unmanageable. Guilt and anger may cause you to completely lose your perspective. Sometimes the best way to really love your care partner is to create some distance in order to refill that well and rebuild resources. At





times, it's not just the person with the “problem” who needs a care plan to guide him or her through what's ahead; you, too, may need a care plan to keep healthy and strong for the journey.

### June Finds Her Wings

*His diagnosis of cancer was totally unexpected. He was the pillar of health. They were both in their fifties and not at all prepared for the many challenges that would follow. One of the biggest worries was financial: While June was a working professional and had her own private business at which she was very good, the creative and expansive side of her did not find expression through her work. June countered the feeling of being both physically and financially trapped by developing a plan. By coincidence and good fortune, she and her husband had purchased a condo in the mountains the previous year, and June's creativity and expansiveness found wonderful expression through the remodel she designed and oversaw. June found renewed energy and stamina for dealing with her husband's situation through this creative outlet.*

*Following discussions with her husband and thoughtful conversations with friends and consultants, June decided to purchase a second condo, a fixer-upper to remodel and resell—with the hopes of making a handsome profit. As these things sometimes go, June's decision to take this risk, to “spread her wings” so to speak, was met with the perfect condo at a very good price. While June and her husband continued to face changes and challenges, June, in a very deep and important way, no longer felt trapped. She looked forward to taking on more projects where she could be creative and in charge. She, her husband, and a group of friends have created a strong team; the crisis, unexpectedly, helped her find her way back to hope and strength.*

### Get Ready

**Ask yourself:** Is caregiving taking up a part of my life—or all of it? If it becomes the defining part, you're probably doing too much. Say so, and ask for some help.

**Reflect:** Try on various feelings. Which ones are you experiencing? You must first accept what you feel before you can address it. Acceptance leads to perspective.

**Speak up:** If you are experiencing any of the symptoms of burnout, say so. Get help as soon as possible.

**Think:** If you're receiving care, think about whether or not you are asking for what you need and receiving it in a way that feels helpful. If not, try to restate what you need at the next care-share meeting in a way that invites the help you want.

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