



Chapter 2: Think It Through

Before you enter into a care-share relationship—whether you need help or want to offer help—it's important to think through basic needs and values, examine your own motivations, and ask yourself if your life will be enhanced by enlisting help from or offering assistance to others.

Basic Interpersonal Human Needs

All humans have a basic need to be in relationship with significant others. It is life enhancing to share feelings, needs, hopes, and fears—and in so doing develop a trust and security with another person. All humans have a basic need to be recognized and valued. This helps create and sustain a unique and valuable sense of self. All human beings have a need to nurture and to be nurtured, to receive care and to give care. Expressing concern, perceiving that concern is received, and accepting the care and love of another contribute to a deep sense of well-being.

When someone is ill or in the midst of a major life change, it becomes even more important for these basic interpersonal human needs to be met. However, this happens at the same time that one's time, energy, and power are compromised. Both care partners and team members need to actively try to recognize and meet their own and the other's needs.

In the following story, a family demonstrates their ability to meet each other's needs in the midst of great adversity. Their common values of openness, gratitude, and caring helped ten-year-old Mario to grow up with resiliency and hope despite being part of a family that was encountering multiple and serious challenges.

When Will I Lose My Hair, Mommy?

"When will I lose my hair?" he asked Linda, his mom. Mario was ten years old when his nineteen-year-old sister discovered she had cancer of the brain. He was ten when his mother's ovarian cancer was diagnosed and eleven when she finished extensive chemotherapy for her cancer that had metastasized. She was given only a 5 percent chance of living one year. That same year, Mario's grandpa received treatments for prostate cancer. And all had lost hair during treatments. Mario's mom smiled at her son's question and said she didn't think he would ever lose his hair.

Amid their tragedies, the family remained open and loving. All members were doing much better than expected. Their friends and other relatives formed a strong care-share team that included Mario and his dad, Walt. This had paid off. Mario took pride in helping his mommy and big sister. Walt continued working without having to take much time off, which helped with the enormous medical bills.

What's more, the care team wrote a vision statement that pulled them together and guided their decisions. Life wasn't all smooth sailing, but it did progressively become calmer.

Linda and Walt expressed gratitude for the care-sharing team. The team members themselves were grateful. The depth of the family's tragedy and trauma had touched and even blessed each one. Each took life and health much less for granted. They were all forever changed by the love and resilience they witnessed and shared. Finally, each team member knew that he or she had truly made a difference in the lives of the family.

There is an old saying that God gave us two hands: one to receive with and one to give with. This means we are not made for hoarding our time, talent, or treasure, rather, we are channels made for sharing. Mario's family really understood the power of this truth. They weren't afraid of asking for—or giving or receiving—help.

Entering New Territory

Asking for help. Giving help. Saying yes, saying no. Feeling uncertain. Not knowing what to expect. Not wanting to

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over commit. Not wanting to disappoint. These are some of the thoughts, fears, and dilemmas you face when you are seriously challenged, ill, or when you are “up close” to someone who is seriously ill.

How do I feel? How will I feel? Will those who will help me feel shame, uncertainty, anxiety, tenderness, embarrassment, and anger like I do? What if I lose it and break down? What if they lose it and break down? What if they're not there? What if they can't do it? What if they really want to help, but I can't bring myself to ask? The questions and unknowns are endless.

Life's inevitable challenges and changes thrust us into new territory. We invite you to enter this territory with humbleness, for surely it will humble you. We invite you to view every encounter as an opportunity to grow. Surely, we all know very little and need to learn more for this journey. This may be the right time for you to come to trust a personal friend or a professional counselor who can help you sort things out. Draw upon the collective wisdom by including others to inform and guide you through the difficult parts of your life journey.

What Is It Like to Be Sick?

Any illness, especially a life-threatening illness, has emotional impact much like a large rock dropped into the middle of a lake. It sends a powerful ripple through the lives of family and friends. They may experience feelings, thoughts, and reactions they've never felt before, which may overwhelm or frighten them. Surprisingly, an illness may even sometimes produce peaceful and reassuring feelings, especially if people step in to help, or if inner work is prompted. Illness always impacts relationships, often in unanticipated ways—sometimes welcome, sometimes not.

Facing a life-threatening illness may stir within you important questions about the meaning of life and what really matters. It also presents an opportunity for you to look deep within and review and reformulate your values, hopes, fears, and beliefs.

In this journey into new and unknown territory, you may feel your innocence is lost, your life suppositions shaken. You may feel vulnerable, not knowing what, when, why, or how. People close to you may seem to be going about their lives as if nothing has changed, yet for you everything is different. You've crossed a line between health and illness, and now you see everything from a different lens.

Receiving Care Is an Art

We believe receiving care is an art that few of us learn in our lifetime. In our three decades of personal and professional involvement with people facing serious challenges, we have met only a few who seemed at ease with being on the receiving end of care. We encourage you to *practice* the healthy attitudes listed below at every opportunity. If you're aware of these qualities when you face minor illnesses or the normal disruptions of starting a new endeavor, then when challenged by the bigger ones, you will know well the territory of receiving care. Begin by thinking about these statements and their truth in your life today.

- I am comfortable with needing help.
- I can recognize and ask for what I need, not more than what I need. I am not overly reliant on others. I also avoid asking for less than what I need and thereby suffering unnecessarily.
- When someone helps me, I feel grateful, not guilty, embarrassed, or shamed.

In the book *Tuesdays with Morrie*, the main character, Morrie, is suffering from a progressive neurological disorder. This will slowly render him unable to care for himself. He knows this and strives to learn, as the disease progresses, to receive in a gracious, pleased, and grateful way. He hopes that people who care for him, after feeding him, or grooming him, or even in his worst nightmare, as he put it, “wiping his ass,” will somehow feel they've given him a precious gift. He hopes that he has received that gift in such a way that those who've helped him will have that wonderful feeling inside them that we all get after we've given someone the perfect gift.

Whatever your change or challenge may be, it's our hope that you'll be able to feel good about asking for, giving, or receiving care. In what may be one of the biggest challenges of all, the beloved minister and columnist Rodney R. Romney wrote the following words of gratitude for the role he'd unknowingly played for his brother.

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Facing Your Own Death

A few months ago in this column I wrote about “Making Friends with Our Own Death.” Little did I then realize that I would soon be faced with the challenge of making friends with the death of a member of my immediate family. My brother, Dick, died on July 18 after a brief but intensive bout with cancer.

We had gathered as a family around his bedside in a hospital room, where he had been struggling for several weeks, when he looked at me and said weakly, “I am tired of this and ready to go. Please pray for me.” I held his hand and prayed that God would bless him and all of us as we learned to let go of life and entrust it into the hands of the One who had created us. As my prayer ended, I felt his hand relax in mine. Within a few minutes, he was gone. I watched the light of life fade from his eyes and felt his heart rate slow down and eventually cease. In the aftermath of that experience, I realized it is sometimes easier to accept our own death than it is to accept the death of a loved one.

This brother was a person who had a great love for nature and its creatures. He had never manifested any interest in organized religion and avoided formal religious services whenever he could. Still, he was religious in his own way, finding his strength in nature and the outdoors rather than in a church. By contrast, I had spent most of my adult life as a minister planning and conducting all kinds of religious services. Yet in those final moments of his life, we were equal, both seeking comfort and guidance from the unknown and unseen force of life.

Several days after his death, as we sorted through his belongings, I discovered that he had kept a laminated copy of my column on making friends with death. I realized then that he must have found meaning in my words, for he had died with peace and total acceptance of the fact that his life was over. I can only hope that when my own moment of departure comes, I will enter into it with as much trust as he had shown.

When you are prepared for what’s ahead, the future is much easier to face. Often, though, you must meet what’s difficult, scary, or unknown before the preparation begins. Illness, injury, and major life changes (even our own death or that of a loved one) come by surprise. Often those who are involved know little if anything about what the care partner is experiencing. Preparing to face the future includes learning about the illness or change, mapping out the possible scenarios and probable journey, and finding out what skills, knowledge, and resources you may need. If you can accept that you are a beginner in this new and often unexpected and unwanted change in life, and move forward as a student, rapid learning will follow. With this will come a sense of stability and control, which will, in turn, decrease anxiety. Replacing resistance with curiosity will diminish your fears. Recruiting and involving friends, associates, and relatives for your journey will immeasurably enrich all of your lives.

Casting a Safety Net

Is the life change you are going through serious enough to seek out more resources or ask others for help? If you are thinking that it’s time to answer this question, then you’re ready to get started. Ask yourself the questions below—whether you are experiencing a challenge in your own life or are considering entering into someone else’s scenario. The answers may not come easily. In fact, prepare to initially want to contradict yourself or to reject your own answers: They can be difficult to accept. However, planning for the worst-case scenario also prepares you for a variety of situations as well as opportunities to make your life better despite the changes and challenges.

Should I Start a Care-Share Team?

- Is my life getting beyond my control?
- Do I find it hard to take care of myself? Think of cooking, shopping, bathing, taking medications (getting them, remembering to take them, coordinating and distinguishing them), staying in touch with loved ones, telephoning, paying bills or managing finances, housekeeping, taking care of children and their needs, transportation, and many other daily tasks.
- Are there people, paid or unpaid, who are helping me or might if asked?
- Am I lonely?



- Am I isolating myself?
- Are the people who are helping me acting as if they're tired or burdened?
- Do I wish I had the answers to more questions about how to handle various aspects of living with my condition? Think of health, finances, insurance, etc.
- Has something changed?

Write out your answers to these questions without judging the answers or strategizing the solution. (We will get to that later.)

Bill Cries, "I Lost My Wife"

Bill and Alice were happily married for sixty-two years. They cared for each other and relished their independence. They also enjoyed a close relationship with their two sons who lived and worked in the same city, and a daughter who lived three hours away. When Alice began to develop forgetfulness and balance problems, the family attributed this to normal aging. As symptoms worsened, however, it became clear that her ability to function normally was rapidly deteriorating. Alice was diagnosed with Alzheimer's disease. Bill was distraught. "I've lost my wife," he thought.

Bill was capable of caring for himself and wanted desperately to help Alice. But as her condition deteriorated, he became more and more tired and depressed. When Alice began to fall and her memory worsened, he worried constantly about her. He doubted his ability to continue being there for her. It was clear that more help or a team was needed to aid Alice as well as to ensure that Bill's own fragile health was not compromised.

Bill's sons noticed the obvious strain on their father. Because Alice's condition was rapidly declining, none of them knew what to expect. Meanwhile, Bill was exhausting himself and isolating himself from his other interests, activities, and friends. He was devoting all of his time, attention, and care to his wife and their home. His family knew this was dangerous. His daughter-in-law, who had participated in a tele-video course called "You and Your Aging Parents," suggested that Bill seek professional help. He agreed.

Bill and his sons met with the counselor, who asked, "What are you doing now? What can your friends do? Have you asked any of them? Can you afford paid help and would it be accepted?"

They acknowledged the current efforts of all the family members. They agreed that some support for both Alice and Bill was well in place, but they still needed more help, which they could divide among family or friends. Two granddaughters, who were high school age and needed spending money, agreed to do some of the household chores and grocery shopping. Their grandpa was happy to pay them, and, more importantly, delighted to spend some enjoyable moments with his two bubbly, energetic granddaughters. The family hired a home-health agency to help monitor and treat the diabetes that Alice had recently developed. Agency aides also helped with morning and nighttime bathing, grooming, and dressing. One of the sons developed a list of his parents' friends, including names, addresses, phone numbers, and e-mail addresses. With the blessing of his dad, his son sent out an appeal for help, informing their family and friends of Alice's situation. People stepped in to spend time with Alice, accompany her on walks, go through photographs, and simply be with her during mealtimes so that Bill could spend some time on the golf course.

The care-share team they developed was a blessing to Bill as he not only resumed his normal activities but also received constant encouragement and support. As Alice's disease, dementia, and disability worsened, the team grew.

At first it's often easy to think you can manage any situation or beloved care partner by yourself and avoid asking for help. However, again we urge you to consider asking. First ask yourself the questions from the above list, as Bill's counselor urged him and his family to do. Then, with the added insight these answers will bring, either begin to take action or seek assistance in doing so. There is much to be gained for yourself and a care partner through creating a personal safety net—a team—to share in the care.

With these questions answered, you've taken the first step to solving the problem. Now you are better equipped to explain to your care-share team what you need and how they might help. You are beginning to create a plan.



As you read on, keep asking yourself how you can modify a care plan to improve life during this difficult time. If you create or join a care-share team you will be maintaining a fine balance of independence, dependency, and engaging in a lot of honest but sensitive communication. Remember, the care partner is in control but needs to use his influence with tact and respect.

The following story tells how Ron had to search his own heart and answer big questions before he was ready to reach out to friends for the help he needed. They, in turn, had to ask themselves if they were ready to say yes.

Ron Takes the Step and Asks

Ron, a 68-year-old former stockbroker, suffered a small stroke that left his right side partially paralyzed. His condition was stable but required a hospital stay, and his long-term prognosis was uncertain. To make matters worse, Ron was still grieving his wife, who had died eight months earlier, and depending upon his daughter, Julia, to help him both emotionally and practically. Now during his hospital stay, Ron didn't want to burden Julia any further. His neurological function was improving, but things were piling up at home. He knew he needed help, but whom to ask and how?

Years earlier, Ron and a group of his friends had made a pact, a promise that if anyone got in trouble, each would be there to help. When Ron made this pact, he had assumed he would be the first to offer, not to ask for, assistance. He was accustomed to remaining silent about health-related problems but he knew he needed to tell his friends of his dilemma. That was their promise to each other. As he prepared to call his "pact" friends, he thought about his wife and how much she had needed him at the end. "Is this my end?" he thought. He missed her now more than ever and wished she were still alive to help him. "She knew me, knew what I needed. She took care of me! I know now what she might have felt."

It was painful for Ron to ask for help outside of his family. "The Korean War was easier than this," he mused. "But I have to do it." With courage and a sense of responsibility to his friends, he called each of them and explained that he'd had a stroke and was in the hospital. Every friend, without exception, asked, "Is there anything I can do?" He replied, "Yes, but I will need your help to figure out exactly what needs to be done and to help organize my recovery."

Ron's taking the risk of asking for help was step one in his new plan. It proved to be a good one. Not only he, but also his daughter, benefited greatly from his courage to ask. Ron's friends stepped up during his recovery: Together they developed and continued to modify a plan that changed as Ron became stronger. They valued his friendship and appreciated him for many things, including his years of military service during the Korean War and his model of how strength could mean enlisting help.

Look at Your Motivations

Have you asked yourself *why* you want to help? Being part of a care-share team may be one way of making a life to be proud of, assuming it is done in a loving and life-giving way. "I'm helping because I can, and I'll enrich my life in the process." "I love this person." "I want to reach out." "This person has done so much for me, I want to give back." Or even, "I'll feel so guilty if I don't." "I didn't help last time, this time I need to do it." These are answers frequently given. There's no particular reason for stepping into a care-share team that's better or more valid than another, but it can be helpful to know why *you* want to do so. Then, if you face a tough period in the life of this team, you'll be able to remember why it is that you said yes. If you are asked why you'd choose to take part in someone else's personal safety net, you'll have an answer. Your answer may even hold some surprises for you.

Clarifying Questions

- Do I want to carry this alone? (I may need help.)
- Am I the only person he/she relies on? Do I want that much responsibility? (Probably not, and a team might



help.)

- Am I experiencing burnout? (A team could help me take a breather.)
- Can I meet my own needs during all of this? (Few of us can.)
- Do I have a good perspective on this situation? (Maybe.)
- Am I willing to adjust my life to revolve completely around this person's needs? (If so, how much or in what ways?)
- Would this person's life be better if there were more people assisting?

Beyond congratulating yourself for wanting to help, look at whether you're expecting to make miracles happen, to put off "the inevitable," to feel loved and needed, or to make someone happy. Knowing why you're offering care can help you recognize successes as well as understand frustrations.

In the book *Gracious Space*, Pat Hughes identifies curiosity and compassion as deeper motivations that cause some of us to want to help: "Bring a spirit of compassion and curiosity: compassion for both the vulnerable and less fortunate as well as for ourselves, curiosity from a deep desire to understand, a capacity to engage, and a willingness to shift fundamental beliefs. . . . In deep curiosity we feel driven to get to know others better, to truly understand where they are coming from and what they can offer to the problem at hand. Deep curiosity is a willingness to hang in there, to seek the gem in another's point of view, even if we don't like the person." Hughes further notes that curiosity and compassion will enhance the lives of both the giver and the receiver. Other motivations such as guilt or a desire for control will not be of much help. But most of us approach a crisis with mixed motives. Becoming clear about your own motivations will help when things get tough.

Set Realistic Expectations

The ins and outs of caregiving, care receiving, and being part of a care-share team may be new territory for you. Thinking through—and "imaging" through—what this might entail will help you prepare and make better choices. You may begin helping enthusiastically, only to discover the situation is more complex than you anticipated. Being able to set realistic expectations and adhere to them is an essential care-team member skill. As you face each new situation, think through how others might feel and what they might think. See if you can talk about different perspectives: This will help you become a better partner. Finally, if you have the luxury to "think through" what's coming with a trusted friend, relative, or professional, there's the possibility of valuable input.

Megan's Story

Megan and her husband, Hugh, created a care team when she needed surgery. They determined that they would need help during the first three to four weeks after Megan's surgery. They began thinking through two difficult questions in an effort to identify what needs or "jobs" they would like care-share team members to do.

The first question was, "What are all the things Megan does now that she won't be able to do during her recovery time?" The answer was that Megan did one heck of a lot, which was both good and bad news. The good news was that Hugh now realized how much she did and began to appreciate this more. The bad news was a lot of work would be left to do, unless someone else picked up the pieces. Megan's first thought was that Hugh could handle it all; he could pick up the slack. Hugh, however, had an equally full life, with his own tasks and obligations. He worried about feeling overwhelmed, exhausted, and grouchy, and missing out on spending quality time with her as she recovered.

Then they asked themselves, "What are the things that Hugh normally does that care-share team members might also do?" Hugh wanted to devote time and energy to being present with Megan, giving her his tender-loving care. Together they decided to ask the care-share team to support them by taking over many of Megan's tasks, plus a few of Hugh's responsibilities.

With this in mind, Megan and Hugh made a list of tasks and divided them into these categories: housekeeping, being on call in case Megan needed urgent transportation, occasionally preparing meals, and simply spending time with close friends.

Hugh and Megan pulled together quite a team. In the weeks before her surgery, they prepared by accomplishing



the following:

- *Hired a paid housekeeper for some household chores (four hours, twice a week)*
- *Asked neighbors to be “on call” for urgent transportation.*
- *Arranged for friends to bring a few meals and stay with Megan for conversation and companionship on nights when Hugh was gone.*
- *Asked someone to return and pick up videos for Megan to watch.*
- *Invited close women friends to enjoy time with Megan as she used her convalescence to begin creating photo albums for her two children.*

Finally, Hugh used his cell phone and e-mail lists and got busy with his help-appeal script. He set aside an entire evening to call potential care-share team members and let them know of his wife’s upcoming surgery. He briefly described some of their needs and asked for help.

He carefully acknowledged that each person had a busy life and simply might not be able to participate. With only a couple of exceptions, their friends and family expressed a desire to help in large or small ways. Delighted and relieved, Hugh got busy organizing this newly formed care-share team via e-mail communication.

When two people have lives that are very intertwined and interdependent, an illness or a life crisis impacts both. Further, if both are working, as is frequently the case, and they share decision making, thinking and talking it through is a major, complicated, and delicate task. Even if it’s difficult, sharing care is certainly the better alternative to receiving no help at all.

Assume You Have Needs, Too

Because it’s important to consider your own capabilities, needs, and expectations as well as the needs and expectations of your care partner, it’s best to enter the care-share situation *presuming* you have needs and *asking* yourself what they are. Clearly and respectfully communicating your needs helps avoid many problems. In Martha’s story below, a friend tells how she balanced Martha’s needs with her own.

Martha

I was not the only person Martha called when she needed help: She asked one person to collect mail, another to grocery shop, and another to drive her to doctors’ appointments. Because she worked hard to make sure none of us ever met each other, we never did. This arrangement went on for months and months.

Most important to Martha was holding the vision of her body as strong, healthy, and whole. This was her hope, through a mastectomy, stem cell transplant, metastases, recurring infections, and, finally, pulmonary failure, pneumonia, and death. But if anyone urged her to accept “reality”—the progression of her disease—she considered them unhelpful and dropped them by the wayside, cutting off communication altogether.

What was clear to me was that I could only participate in this unformed “team” if I could suspend disbelief enough to hold Martha’s vision of health, mirroring it back to her through thick and thin. This was her life, and I decided I could do this for her. Yet I could only commit a couple of hours a week to her because of the strain this caused me. To do more I would have needed a cohesive team—just what she was avoiding! I gave what I was comfortable with and did that gladly since I stayed within my own comfort zone.

Balancing the needs of the care partner with your needs, as well as those of the other care-share team members, involves getting to know yourself better. (To read more about balancing needs, see *Take Care of Yourself* in Chapter 5 and *Burnout* in Chapter 6.)



Now that you've asked yourself the hard questions, examined your values and motivations, and learned a little more about what caregiving and receiving is all about, you're getting ready to take the next important step: Asking others for help. It's not as hard as you think. Read on to discover more.

Get Ready

Ask yourself: What do I value most in life? (Write down your five most important values.)

Think: Do I believe that relationships with others are important? What are my five deepest relationships? Do I believe that it's important to both give and receive care?

Remember: When did I help someone out or someone helped me, and it felt good? Was there ever a time when it felt bad? Can I remember why?

Practice: List the steps needed to tackle any task in front of you, then prioritize them.

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