



Chapter 7: Watch for Stumbling Blocks

Most of the problems encountered in care-share teams can be resolved. We believe it is helpful to learn about potential problems from the stories of other people's real-life dilemmas and how they solved them. As you expand your personal safety net, surround yourself with people who've had a broad range of experiences, ask them about their challenges, and learn from them. You will be better prepared to avoid or effectively deal with care-share problems if you can anticipate them. This chapter is our attempt to identify some stumbling blocks that we've most frequently encountered.

Emotional Traps

You can expect that feelings of dependency will evoke strong emotions. People typically love to be needed, yet hate to be in need. "Needy" has such negative connotations that are hidden behind a pretense of having it all under control. We act as though having life under control means doing it all ourselves, or paying for help, but rarely asking for assistance. In the book *Still Here*, Ram Dass has observed that "being dependent, needing help, makes us feel diminished, because we value self-sufficiency and independence so highly. We value taking care of others, but shun the notion of being taken care of ourselves." You *can*, however, balance your independence with an ability to ask for help.

In addition, many of the emotions mentioned in earlier chapters are related to other "hot buttons," that, like dependency, are easily pushed: for example, guilt, fear, anger. Naming these takes away a lot of their power. Asking fellow team members for support in identifying when old patterns show up and in finding new ways to respond can help you avoid automatic responses.

Another trap is that of jealousy. You may feel your relationship with the care partner is threatened just by others forming a care team. This can be self-fulfilling.

Elizabeth and Her Daughter

Elizabeth needed help in taking care of her young daughter. A single mom with some serious health problems, Elizabeth was fiercely independent, though overwhelmed by parenting and considering putting her daughter up for adoption. Eventually, a school principal won Elizabeth's trust and supported her in seeking temporary foster care for the little girl. Another school family stepped up and received training

and certification to become her foster parents. It should have been a big red flag that, at this point, Elizabeth dragged her heels in actually placing her daughter in the official foster care system, as she had agreed upon. This was the first time Elizabeth would act counter to agreements, and it was a passive-aggressive response to her unacknowledged fears and jealousy. Instead of speaking of these and enlisting even more support from a team, Elizabeth pushed for the girl to immediately live with the foster family "until the process was complete." The truth was that Elizabeth feared that her daughter would thrive in the new family system and even love her less as she came to love the new family more. The family, with reservations about this sequence, nevertheless agreed to take in the girl, even though she wasn't officially registered in the foster-care system.

The young girl blossomed—that is, until Elizabeth's jealousy over her daughter's successes caused her to sabotage everything. Elizabeth would abruptly call her daughter home and accuse the host family of imaginary slights or ill intent. The host family had no official recourse because the girl hadn't actually been placed in foster care. Repeatedly this happened, until, no matter what successes the progressively older girl experienced, she no longer believed that they would be lasting, and she began to sabotage her own efforts. The team that was ready to support mom and daughter never really could take shape because of Elizabeth's fear, jealousy, and lack of honesty, which caused pain for everyone involved.

Too Many Needs

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A care partner may have infinite needs, wants, or preferences. And while he should feel free to express these desires, you and the rest of the team may not be able to meet each and every one of them. And care partners will often have difficulty accepting that team members—who already feel pulled to make everything better—can't do *everything*. Together, though, the team should attempt to fulfill only the needs and wants that can be comfortably and reliably managed. You can devote your energy to identifying and finding resources from a broader personal safety net for the remaining tasks.

Prioritizing needs is a skill that you will develop over time. As mentioned in Trisha's story in Chapter 4, one team we worked with prioritized their tasks this way: First, an action had to be *safe*. Then it needed to contribute to the care partner's *security*. Next, it had to be *simple*. And this safety, security, and simplicity had to lead to enhanced *serenity* for the care partner.

Using this team and its priorities as an example, you and your team can support one another in recognizing individual safety, security, simplicity, and serenity limits and preferences, too. One person may only be available mornings. Another might be willing to send e-mail messages or make phone calls. A third might organize meals or carpooling for kids. One might be best suited to accompany the care partner to doctor's appointments.

Once you and your team have determined how to meet the most critical needs, you can seek community resources to tackle the other tasks. Consider contacting organizations that focus on seniors, single parents, various illnesses, or one of the many religious organizations and other entities that exist to meet needs in the community. You can find this information in the yellow pages, on the Internet, and through the organizations we've listed in the Resources section in the back of this book. You might also think of someone else to ask to join the team or brainstorm alternative strategies. Becoming familiar with these resources is another way to stretch your safety net.

Mix-Ups

Not everything goes perfectly smoothly. Even when your team appoints a leader or coordinator to assign specific times or tasks, a team member may just forget, drop the ball, or disappoint your care partner. Even if there are rosters and phone trees, and no one moves, loses a cell phone, or erases a database, there will still mostly likely be times when you forget something. This is just life.

What can you do when someone "goofs" or miscommunicates? You could gently bring up the misunderstanding at a team meeting—not to assign blame, but to learn, improve, or make changes. Asking not "who was to blame" but rather "what factors contributed to this mix-up" is often useful in gathering data and preventing similar "goofs." Be willing to laugh and keep things in perspective: This can be healing and leveling.

Alternatively, if someone regularly drops her agreed-upon tasks, or if you follow a process that gets in the way rather than facilitates the care partner's health, assess what's going on and address it.

The Bossy Person

Some people view entering into a care-share team as their chance to "save" or "fix" the care partner or the situation. This is a typical response to wanting to help. Yet the entire team should remember that supporting, not fixing or saving, is the goal. Someone who wants to fix can tend to have specific ideas of how this should be done. But those "fixes" may not be what the care partner wants or needs—or even what the team can do. Group process can be a good balance for that, even if it is sometimes frustrating when it takes longer.

Being a member of a team has components of responsibility, while also demanding the relinquishing of control. A bossy person will be challenged to grow and behave more collaboratively as fellow team members become better at softly but firmly standing their ground. If someone becomes rude or starts bullying others, however, this is a different matter altogether: The group will need to work together to intervene—or perhaps this person herself needs to take a respite, seek counseling, or permanently leave the team. If the team member needs to leave, then, if possible, acknowledge whatever contributions she's made in the past as part of her leave taking.

A Crabby Care Partner



From time to time your care partner will probably feel emotional, fearful, or crabby. This may feel personal. It may be challenging. It may be too much.

Ben's Anger after His Stroke

Ben had always been independent and very clever at fixing things. After retiring from forty years as a Boeing engineer, Ben was happy to turn to the many home and hobby projects stored up for this time. He was totally caught off guard when he experienced a debilitating stroke. He felt cheated and robbed by the changes in his body. Ben eventually recovered most of his speech, as well as the use of his left arm and leg. However, he was a real challenge to be around due to his bitterness and anger. He would constantly lash out at others, and himself. Fortunately, as the months passed Ben slowly recovered and he became able to resume his projects and hobbies, and his bitterness and anger lessened. He even came to express some appreciation for the help his wife and other caregivers had offered. Without the team support, they added, they'd have burnt out long before. In the end, team members could honestly say they were glad to have helped.

One way to deflect a care partner's criticism and negativity is to prepare responses, such as "I hear how hard this is for you" or "I can only imagine how it seems from your perspective." Practice these before you need them. Get help in thinking up responses that are right for you.

Sometimes, though, whatever the situation it may be too much for you. When you're feeling overwhelmed, after making sure the care partner is safe, take a break and rejuvenate yourself: Walk around the block, call a team member for advice, take a soothing bath, do something artistic, or schedule time with a therapist or another person who is part of your own personal safety net. Do what you need to renew your sense of perspective. Don't let a crabby care partner drive you away from the chance to help and enrich your life.

Fears

It is perfectly normal and understandable to have some of your own fears, particularly when facing an illness, injury, or the unknown. Whether you are the person receiving care or someone who cares about that individual, fears will crop up. Naming them usually helps diminish their potency. Understanding your fears will help you avoid the kind of distancing behavior we've been addressing. Some fears that are fairly predictable are these:

Care Partner's Fears

- If I ask, will they say no?
- What will I do if they say yes?
- Will others be telling me what to do?
- If they help me now, how will I reciprocate? How can I ever pay them back?
- Will I lose control, privacy, or self-sufficiency?
- Will everyone know my problems?
- Will I need to go to an institution?

Team Member's Fears

- Will I be overwhelmed?
- Will I be able to do what's needed?
- What if she has a seizure or dies?
- What if I can't make things better?
- Will I have to do things that are too personal?
- What if I get sick, too?

In our experience as caregivers, we have heard people voice these fears—and successfully answer them, too. How you answer these questions will depend a lot on your unique history of experiences and your current circumstances. But we have found that saying them aloud or writing them down definitely helps.



Norma's Fear of Retirement Homes

Everyone who cared for Norma—her daughter, her son-in-law, two close women friends (who, like Norma, were also in their eighties), a home-health nurse, and a care manager counselor—agreed that Norma's memory problems and love of people could best be addressed in a retirement home. But they were stymied. Norma would visit lovely retirement homes, enjoy a meal there, chat with female residents, and seem to have a marvelous time. Yet at the last moment she would refuse to move. With time and sensitive conversations with a counselor, it became clear that Norma's reluctance stemmed from two deep fears. The first was historical:

When Norma was eleven years old, her mother was placed in a tuberculosis sanatorium, which traumatized the whole family. She also feared that if she moved into a retirement home, she would forget how to do things, become old and dependent, and lose the love and respect of her family. Norma's team, despite heroic efforts, failed to allay these fears.

Norma did not move. Instead, her needs grew beyond what her care team could meet. Her safety net was not strong enough. She persisted in making unrealistic demands. Despite the best efforts of her small team, Norma's situation spun out of control, including many visits to the emergency room, police involvement, adult protective services, and attorneys.

Finally, it was determined that her risky, unrealistic, overly self-reliant behavior was a clear danger to herself. Still refusing to accept reasonable help, she had the right to self-determination taken from her and she was moved to a protective environment.

It's often true that when someone moves into a care facility, her world becomes smaller and smaller. The only information from the outside world may come through the television news, with its focus on crime, violence, and destruction. Even reading a newspaper may reinforce an isolated person's sense of powerlessness. This can cause distrust and anxiety. As Ram Dass said in the book *Still Here*, "When you shrink your world to your immediate surroundings, you end up trapped by them." How you respond to your care partner's fears and anxieties depends on particular circumstances, resources, and individuals. Clearly, though, compassion is called for—and again, humor. What are the fears and concerns? Can you help put words to them, even if they sound silly?

Depression

Grief is often confused with depression. And while the two states have much in common, there are some important differences. Grief is a normal response to an event or a situation experienced as a loss. Depression is an abnormal psychiatric disorder marked by persistent feelings of hopelessness and dejection, and sometimes by suicidal tendencies. Grief can lead to depression if unresolved. (Read more about grief in Chapter 8.)

Depression is a very serious condition and needs treatment. If you think you might be experiencing depression, seek help from a trained mental health specialist. Or if you suspect that someone you care about might be depressed, it's important to find out how to recognize depression. A good place to start is this list compiled by the U.S. Department of Health and Human Services for older adults.

Loss of Control

In care-team relationships, as in any intense interpersonal experience, personality conflicts may arise. If your values and beliefs differ from your care partner's, this can cause friction. There are endless examples of how a care partner's and a team member's values may clash: Should you phone the doctor if the care partner shows signs of a slight fever and begins to cough, or only if he has difficulty breathing? Should the care partner dress himself, even if it's a laborious process? Should you inform the physician when the care partner exhibits new symptoms or honor his request to keep them "private"? Do you go ahead and install bars in the bathroom to prevent a care partner from falling, even when he hasn't requested them? As a team member, you may find yourself constantly weighing freedom versus safety, or honesty versus privacy.

In each of these scenarios, there's the possibility for the care partner to either maintain or lose control to some



degree. There's also an opportunity for dialogue and increased understanding. It's important to remember that the care partner is the one who ultimately will live with the situation, and is the one who has the last word.

If, after discussion, you and another team member or your care partner still disagree, consider bringing the issue to the whole team to brainstorm a solution. Or seek the help of an experienced yet neutral third party, perhaps someone from Senior Services, a trusted family friend, or a trained counselor.

When making decisions that directly affect the care partner, carefully and compassionately think about all the areas in which she may be forced to give up control, especially if the issue is related to injury, illness, or advanced age: mobility, autonomy over simple daily tasks, privacy, personal appearance, bodily functions, and much more. It won't be easy for her to give up control, so tread delicately here; do the best you can to preserve her dignity.

If you're generally considered a "control freak," being a team member will be a great training ground for learning to let go. Even if you just want to be in charge of your *own* life, others may perceive you as overly controlling or bossy, though this may be far from your intention. Try to express your need for control by framing the issues broadly. Try to be curious about other ideas and possibilities. You control your own actions and reactions. You control how you define your needs. You cannot, however, exert control over anyone but yourself. Curiosity and compassion, once again, will be valuable tools.

Sharon and Rosie

Sharon was an African-American woman who had fought her way to success in her career. At forty years old, she was diagnosed with a terminal illness and given less than six months to live. But dying just wasn't on her radar screen. So she fought. She fought as she'd fought so many things in her life—and wouldn't admit that she had a disability or was dying. Still, it wasn't long before her doctors and family placed her in a Hospice setting.

Usually people who enter Hospice care say that they wish they'd done so earlier. But not Sharon. She continued to argue and fight, which made even running an errand for her or taking her to the park a difficult task. Friends and family found it hard to feel close to her and began to stay away. In the end, she had a hard fight and a lonely death.

Then there was Rosie. She, too, was African-American, successful, and under sixty. She had not expected her diagnosis, but received it with the grace with which she'd encountered much of life. The details of her illness, and her timeline, were similar to Sharon's, but Rosie's approach was to work with what came her way.

Rosie asked for help. She was going to find a way to take care of this task, too, as she'd taken care of so many, with love and dignity. She said that she was the only one in charge of the quality of her life. She would choose how and with whom to spend time, what to think about, what to pray for. Even in dying, Rosie chose well-being in every moment.

Within six weeks of her diagnosis, Rosie was dead. And though her death was no easier physically than Sharon's, for Rosie it came without argument or anger. Rosie died, as she had lived, with compassion for herself and others.

Too Much Help

Through our hands-on experience giving and sharing care, we have learned to identify many common "helping strategies" that actually complicate the situation or cause problems. Many of these attitudes and behaviors, while well-meaning, may cause a care partner to become weaker or more dependent upon you:

- Solving a problem for her because it's faster or easier for you to do it.
- Giving help before it is requested or without asking if it is wanted.
- Providing more care than is good for you, and thereby risking feeling overwhelmed or stressed.
- Not allowing her, if she wishes, the opportunity to try something where she may fail.
- Speaking for her.
- Needing her to need you.



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- Not being honest about what you need or want.
- Overly protecting her from honest feedback about her words and actions.
- Trying to cover up or hide the reality of her situation.

In contrast, we have observed that when care-team members demonstrate the following attitudes and behaviors, they allow care receivers to develop and use their strength, flexibility, and resourcefulness.

- Openly and honestly communicating with the care partner.
- Clarifying roles, expectations, and limits.
- Communicating, negotiating, and partnering with him about what each will attempt to do.
- Being consistent and dependable, feeling responsible *to* but not *for* him.
- Doing your best to clarify assumptions and ask for feedback.
- Remembering to reach for humor and humility when other tools elude you.

Get Ready

Think: Can you separate being needy from asking for help?

List: What scares you? List even the fears that sound silly.

Get help: If you've seriously or specifically considered suicide, call 911 or your crisis center.

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