



Chapter 5: Keep the Team Going

Joining a care-share team will bring both rewards and challenges to your life. People who have been part of teams speak often, and with passion, about the rewards they experience: a sense of connection, a greater awareness of the gift and fragility of life, and new wisdom gained from working with others. Being a part of someone's safety net in this way can be tremendously rewarding.

But, realistically, at times helping won't feel good—because of time pressures, a cranky care partner, personal business that's being put off, and many other reasons. You may feel others are making unreasonable demands of you. You may feel guilty about not being able to accomplish everything. You may feel negative even when the care partner expresses gratitude for your help. For most people, though, these negatives pale in comparison to the positives. In fact, Multifaith Works, a Seattle nonprofit that invites people to join interfaith care-share teams to support community members with HIV/AIDS or multiple sclerosis, has more volunteers than it can train. The word has spread that caring for others feels good.

In our years of caregiving, we've discovered simple strategies to maintain this goodwill within a group.

Schedule Ongoing Meetings

Schedule regular check-in meetings. Encourage members to share experiences, concerns, and schedule conflicts. Many care-share teams reduce problems by routinely discussing how to cut back, take a break, or switch to less demanding tasks. Regularly scheduled meetings provide a forum where team members can ask for help if they're feeling overwhelmed. Sometimes professionals come in to train volunteers in specific aspects of the work.

Participating in a group where it's okay to speak of burnout, change, or cutting back creates a positive experience for everyone. It's only human to occasionally feel overwhelmed or tired; in the care-share team these feelings can be countered with information and, perhaps, training. Such feelings are normal, expected, and can be aired in a safe, supportive context. Regular meetings can function as a safety valve. This is the place where folks can speak of all the feelings that arise out of participation, find compassionate listeners, and adjust roles and responsibilities.

Sticking to a set meeting schedule eliminates the need to repeatedly work out a new one. Once a month or once every other month is probably enough to keep things flowing, although some teams, especially during very difficult or intense times, may need to meet weekly. At each meeting, your group will want to accomplish the following:

- Check in with each other regarding events, emotions, or commitments that will affect the ability to be part of the team.
- Update the care partner's needs or schedule. Prioritize tasks if there are too many needs or wishes for the team to fulfill.
- Adjust the schedule to address ongoing or newly identified needs. Delete tasks that are no longer needed.
- Share pertinent information about the care partner. Keep in mind: This is not a gossip session, but rather an opportunity to learn what it will take to do a better and more compassionate job of support.
- Celebrate successes; have fun and play together to build cohesiveness and camaraderie.

If you participate in a care-share group that also includes the care partner, you will sometimes want to meet without him in order to freely air feelings that might hurt or offend. You can handle this in a straightforward way, reminding the team about the need to care for his heart. Team members must do their best to be honest but tactful with themselves and their team.

At times, though, it's helpful for the care partner to attend the team meetings. In the story below, a care-team member describes how involving her care partner in meetings and decisions benefited the whole team.

Care Partner as Care-Team Member

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Although it is probably somewhat unusual to have the care partner as a regular member of the team, we include her in our team. Occasionally we've met without her, but I can't imagine how we'd have gone forward without the input of our care partner, who has a life-threatening progressive and episodic genetic disease. Over the years she's brought up not only issues for us to brainstorm but also terrific resolutions. Only she knows how she'll feel, and having her present allows her to share these feelings. However, there are also disadvantages, which we've worked around. Her medications have made her loopy or suspicious at times. This can be difficult or funny, but sometimes results in feedback about the side effects of medication to relay to the doctors. Overall, we've found that engaging our care partner in our regular meetings works well because she gives us her direct input so we can discuss options in the moment.

As a general rule of thumb, however, the care partner does not always participate in the team meetings. She may be too ill, young, tired, stressed, or compromised to take part. In fact, you can think of the situation as similar to holding an executive board session. Your team may be talking about feelings, scheduling challenges, or group dynamics that are solvable, but may present an unnecessary burden and anxiety for the care partner. You must use sensitivity and make decisions on a case-by-case basis, inevitably through some trial and error.

Communicate

Frequent communication is as important as regularly scheduled meetings for team cohesion and team performance. Good communication begins with the team leader, who can take meeting notes, send them to everyone on the team, and use the notes as a tool for keeping everyone working together. The team leader also can regularly update schedules to maintain team member involvement and keep the information fresh. Even the smallest gestures can build team cohesion, such as asking everyone to pitch in to a collection kitty to cover the cost of stamps, paper, and envelopes. Be careful to communicate openly, not selectively, to avoid having some team members feel left out. A care partner's issues can trigger a team member's memories or fears. Everyone's feelings can be pretty raw when the care partner is going through a crisis or dealing with the pain and fear of a terrible illness, loss, or injury. Feelings can be easily bruised or hurt, so find ways to let every member know what's going on and that they are important. It is everybody's job to support each other.

Besides meeting notes, other useful tools are a phone tree and a group e-mail list. If you've had school-age children, you're probably familiar with the phone-tree way of relaying information from one person to another. Here is how it works: The care partner (or team leader) phones one person with information regarding a crisis or concern. This person then calls two or three others, each of whom then calls two or three more. If someone does not answer the phone, then an additional call needs to be made to the next person on the list until a voice-to-voice contact is made. Action may be needed, so it's crucial to take this step. Depending on the sensitivity of the information, messages can be left. Obviously, it's important for everyone listed on the phone tree to have an up-to-date copy of it. Here's an example:

If you're using an e-mail group list, it's equally important to make sure each e-mail address is current. Ask for confirmation of receipt, since even the Internet isn't foolproof. And be sure to set up an alternate way of reaching those who don't have access to the Internet. In case service is down, it's a good idea to have both phone and e-mail information, whenever possible.

Maintaining a method of communication, such as a phone tree list or group e-mail list, helps the care partner feel connected to the rest of the team. The following story dramatically illustrates what can happen when no communication plan is in place. Violet intended to keep information about her situation close to her chest, sharing only portions with selected people as she thought they needed to know. The dramatic results were unintended.

Violet's Selective Communication

Violet received the information that her cancer had returned with her characteristic determination and denial. She could tolerate only those people who would support her in looking toward a completely renewed healthy future, and so she shared only pieces of her medical situation with most people. She had created her own care-share team, made up of individuals who, for the most part, didn't know, or even know of, the others. Violet didn't trust that these friends or associates would be at her side if they met one another or knew the full story. She feared that if they met each other they'd form friendships and would abandon her. Her sense of safety kept her operating as



the hub of a wheel with her team members scattered along the rim, separated from one another by the absence of any roster, meeting, or overlap.

This worked out all right while Violet was mostly able to live at home. It all fell apart, however, when she was hospitalized a few months before the end of her life. With no one holding Health Care Power of Attorney, doctors were unable to inform anyone about her wishes. The hospital confidentiality policies and the Health Insurance Portability and Accountability Act of 1996 (HIPAA) prevented friends from visiting her on the intensive care ward. Several of those who had actually been quite close to her didn't even know what was going on or where to find their friend, because no one else knew of her relationships. They were concerned and fearful on her behalf, yet had no way to get information. At the end, Violet was quite alone.

For this team there was no closure. Weeks went by until a distant relative came forward to sort through Violet's things. This person found names of her care team and pieced together the story. The group, however, never did coalesce.

Honor Your Commitments

Remember, it's important that team members take their commitments seriously. Sticking with tasks and schedules creates a safety net for the care partner. Unfulfilled promises and unfinished tasks have a negative impact on the care partner's life and force another team member to pick up the pieces. As Alexander Pope said, "To err is human, to forgive, divine," but because this is probably a time when nerves are a bit frayed all around, it's wise not to ask for too much on the divine level from human compatriots. It's best to let others know as early as possible if a commitment can't be honored, for whatever reason.

Although commitment is important, so too is flexibility. However, if you're considering whether or not to participate, or whether or not to include a specific individual, it's important to speak to the issue of taking on only those tasks or times that are truly going to work, as best as you can foresee. Each person will have different amounts of time, skills, and areas of expertise. Some may volunteer on a daily basis, others once a week, still others every month or "on call." In some cases team members may provide professional backup to mediate, give counsel, or encourage. Other members may call, or pray, or send love. What's important to remember is that all contributions matter.

Evaluate how much you, or others, can commit to a potential care team. You need to be clear, in your own mind and with others, how much and how often you can offer help. Schedules, cell phones, and computers can help the team keep in touch, but no tool will help if you simply don't follow through.

Build Trust

We like respected psychologist Dr. Oscar G. Mink's definition of trust: "A person's confident expectation that another person's behavior will be consistently responsive and supportive to the mutual interests of both persons." Trust has also been defined as confidence in and reliance on good qualities, especially fairness, truth, honor, ability, or responsibility. However you define it, trust is important in a care-share environment. You can build trust by being consistent in doing what you've promised, maintaining confidentiality, and remembering to focus on your care partner's needs. Having a sense of humor, taking care of oneself spiritually and physically, and bringing difficulties regarding caregiving to the group will all deepen trust.

For the care partner, trusting in the people who have come together to help him can be, surprisingly, a challenge. This kind of relationship may be new: Relying on others in ways you never even imagined can be hard. For example, if your care partner's world has been reduced because of mobility issues, people who are late can cause him great anxiety. He may question your loyalty and wonder if you even care. Having someone drop a task, even unintentionally, may raise doubts and fears. If someone questions his preferences or offers a different point of view, he may feel attacked. Learning to trust will take time.

Forming a "perfect" trust among care-share team members can be tricky—and humanly unlikely. But discussing problems openly, acknowledging mistakes, keeping a sense of humor close at hand, and recognizing that we all do things differently are important ingredients for building trust among team members. Equally important is having a

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clear understanding of who is going to do what and when. Once trust is broken, it can be hard to reestablish, especially if it goes unmentioned. Trust should be held gently.

Enter Carefully into Someone Else's Life

It always seems like a sacred invitation and act of trust when a person allows you to come within the boundaries and borders of her life. Respectfully acknowledge what an act of courage is being made when your care partner opens her more personal, private life and needs, vulnerabilities and fears, hopes and dreams. You are a guest in her private world. Be careful, go slowly, and honor this special circumstance.

Acknowledge the sacred trust not only of the care partner, but also of her family. Every family has its own shape and dynamics. When you, as a nonfamily team member, enter into this complicated realm, it's because you are needed. There is much you don't know about this family. And, while you're a valued team member, you're still not privy to years of history. It's important that you, as a team member, try not to judge or to fix families nor get into the middle of complex family interactions. The family will most likely welcome you—and the care partner's life will be enhanced—if you are respectful and supportive, but not invasive. Let trust build gradually. Ideally, you and the care partner will have been in the same safety net for years, experiencing the give and take of personal communication and establishing a respectful intimacy.

Take Care of Yourself

We cannot give what we do not have. A Native American saying reminds us, "You cannot give someone a drink from an empty cup." When you help someone, even though you might be glad to do so, the effort can be demanding, especially if there is no apparent improvement. Don't be surprised to be occasionally emotionally drained through the effort. It's also true that the effort of helping another is enriching and rewarding—so how can we find the balance? Below we've reprinted the advice of some retired residents of Providence Mount St. Vincent, a wonderful continuing care facility in Seattle, Washington. There the residents are encouraged to look beyond themselves to the needs of others. This is their wisdom—how they charge their helping batteries—as it was submitted to their in-house newsletter.

- Understand that everything has a purpose: Be curious and discover it!
 - Make time for a friend, even if you're tired.
 - Find a way to stay productive: Someone has a need just for you to help with.
 - A smile is ageless.
 - Take time to really look in someone's eyes and just enjoy the quiet.
 - Be grateful for the blessing of wonderful people in your life, even when they pass on.
 - Have faith in God's plan.
 - All the trivial experiences will pass by; what's important will stay with you.
 - Be amazed at what you can do.
 - Life is to live—have a good time of it!
- Published in *Living*, Summer 2004.

Experiment and figure out how to recharge your own batteries: be it a walk in the woods, a raucous concert, or the smile of a baby. No matter if you are the caregiver or receiver, take time for nourishing yourself.

Respect Boundaries and Roles

One common way you, as a caregiver, can get overwhelmed is by forgetting to take care of yourself. If the care partner's needs become so paramount that your own personal needs are ignored, problems will surely follow. Boundaries (or limits) and roles are tricky and subtle. Boundaries are too loose when care team members proceed beyond or behave outside specified and agreed upon roles and the behavior appropriate to that role. For example,

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if a paid younger caregiver begins acting like a daughter, with corresponding expectations for maternal solicitude from the older woman she cares for, this young woman would be violating a boundary. Or the converse would be true if the older woman gives advice, money, or gifts to the younger caregiver, as she would to her own daughters.

Entering into a care-share team can be somewhat like going into a foreign country. You will need to try to understand and respect the expectations, sensitivities, customs, and needs of the care partner and his family system. Sometimes the care partner or someone who knows him well can help. Sometimes the team may need the assistance of a translator or counselor. But unless these rules are communicated, no one will be able to follow them. Awareness, curiosity, and respect will help the whole team understand the boundaries of this new land.

Sometimes boundaries and roles, rather than being forgotten, are too firmly and rigidly held. An example of this might be when a friend joins a care-share team and performs her responsibilities in an overly crisp, businesslike, even cold fashion, focusing only on the task at hand without showing compassion to the care partner. Caring for feelings and each other's hearts is imperative.

How do you know when you're approaching a boundary line? What's just on this side? What's on the other side? How do you stop? If only personal boundary lines were as easy to discern as property boundary lines: You could get a survey and know for certain. But personal boundary lines relate to subtle—sometimes intangible—issues such as personal space, privacy, body functions, religious beliefs, family relationships, and deeply held hopes and fears. We believe you should go slowly. Be quick to communicate, to apologize, and to correct your course of action. This is new territory, where you all work together to discover what works and feels right and what doesn't. Make the needed changes along the way. Your personal growth and increased connections will be your reward.

A friend shared this story about struggling with boundaries. Her compassion for her friend had brought her dangerously close to a personal edge of fatigue, discord with her husband, and emotional distress.

Only Friends

"Will you be my friend?" has been a defining question of mine since I was little, maybe three or four years old. Though I've never had dozens and dozens of friends, I've predictably had a handful, and treasured each for her or his gifts and place in my life. I can't remember ever having a "best" friend, even in grade school, when such alliances were common, and commonly endangered. I've always had a few very good friends, though. Many times these friends were in turn someone else's best friend.

So, it was with some sense of alarm that I heard my care partner refer to me as her best friend, her only friend. What could this mean? What about my husband, the closest friend I'd ever had, who, though supportive of my role in my friend's life, also wanted more of my time? It raised a level of anxiety that I neither welcomed nor understood. I struggled with a sense of confusion and dismay.

The idea of her being a best or only friend to me, I discovered, was accompanied by feeling overwhelmed and engulfed by the personality, needs, and complexities of my care partner. Through many conversations with her and some counseling, I came to see that what she intended was a testimony to our growing fondness for each other. She "labeled" our relationship this way so that she could freely ask for help from me. But I felt it was a scary weight. I learned that throughout her life she had customarily had one "best" friend, clearly a foreign concept to me. Moreover, it was my problem, and one of boundaries.

After several weeks of prayer, journaling, and talking with a counselor, I became clear with myself, and then with her. While I could not be comfortable at all with the thought of being an "only friend," I could be delighted to be her best friend, as long as she understood that I could not reciprocate. Meaning no disrespect to her, I simply wasn't about to relinquish myself to having only one friend, or even one best friend.

Through all of this, I learned that while I can be a very, very good friend, I cannot be an even adequate only friend: It's simply not something I can do. Thank heavens she could understand and accept what I was saying and what I could offer.



Play and Rejuvenate

What do an ice cream social, a silly white elephant gift exchange, May Day flowers, and brown bag picnics have in common? They are ways in which teams can have some fun while celebrating their partnership. Monthly potluck dinners fall into the same category and allow teams to socialize *and* take care of business. Other teams we've known celebrate birthdays, go bowling, or create collages. Get creative with your team and decide what would serve your needs.

Mental health is improved if there is a focus on something or someone else and if there is laughter in life. Being part of a safety net by participating in a care-share team definitely provides the opportunity to focus on others. And playing and rejuvenating will help balance the team's perspective, even in the midst of inevitable frustrations and tensions.

Keep Rituals and Traditions

Rituals, traditions, and ceremonies also help maintain a positive balance in the emotions of a team. You can create rituals around welcoming someone new into a team, opening or closing meetings, saying good-bye to a team member, or periodically celebrating the group's ongoing existence.

Gathering visual or mental images, writing group thank-you notes, burning papers that represent resentments or good memories—all of these efforts channel emotions in positive directions. Art can open the heart: Capturing memories with a note, photo, picture, collage, or piece of artwork is one way to start. Water represents renewal and cleansing. Fire is purifying and signals letting go to a higher power or the universe. Sharing food is a common gesture of welcome and trust.

Rituals can also function as a way—even a habit—of acknowledging the contributions of team members: Set aside time at each meeting to say something positive about the other team members. Give each person the “floor” for a few moments during every meeting to report on how things are going. Post a photo board of names and faces, and list ways each person has pitched in. The idea here is to clearly identify what each person has contributed and celebrate it.

Some people use rituals and ceremonies to say good-bye to their homes—or their independence. In the following story, a counselor tells us how Rita used a bittersweet ceremony as she left her much-loved home and moved to an assisted living facility.

Rita's Good-Bye to Her Home

Into the first room we went, Rita in her electric wheelchair and me following her. Rita slowly scanned the room with her camcorder. Tears rolled down her cheeks as she began to speak. She described first seeing the house, then deciding that it would work given her growing disability, and finally making it into a home—her home.

Now it was time to say good-bye. Moving from room to room, she repeated the following ritual: She read a short thank-you to each room for its service to her over the years; then she lit the note with a candle, burned it to ash, and added the ash to the potted plant she would take to the assisted living facility that would be her next home. She lingered in her craft room, where she had spent many hours in the creative process, making gifts for others. It had been an important and fulfilling form of self-expression. We circled back to the living room where we had enjoyed many cups of tea and meaningful conversations.

She thanked me for accompanying her on yet another leg of her journey. She seemed at peace and ready to say her final good-bye to this home she had loved.

Get Ready

Communicate: Set up a system and try it out. Occasionally ask team members how it's working. Tweak as

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needed.

Acknowledge: Make it a practice to thank each other for the work accomplished on behalf of the care partner.

Remember: Take time to laugh and play.

Be brave: Look in the mirror and say out loud three statements that you feel strongly about but find it hard to say to the person who needs to hear them, such as, "I'm angry about missing my own family dinner when Susie doesn't show up on time," or "I'm scared to be with Mitch when his parents aren't around." Sometimes just saying these things aloud takes away their power. Speak your message with feeling.

Be productive: Keep meetings brief. Agree upon a schedule. Stick to ground rules. Try out ideas.

Pay attention: Do you feel good about your involvement? Take care of yourself, too.

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