



Chapter 8: Prepare to Say Good-Bye

Few things last forever, including care-share teams and your participation in one. Acknowledging this reality from the start is a good step toward coping well when someone leaves the team, when the care partner gets better and no longer needs the team's help, or when the care partner dies. Some teams, originally centered on an illness or major life change, shift purpose and continue as some form of organized friendship. Most teams end, however, within a year. But many people find that, though the care team they've grown to love and appreciate may dissolve, they can continue to share their compassion and use their new-found skills as part of yet another person's care-share team. People who have been helped often go on to help others. People who have helped once—and who have had a satisfying experience—often say yes to new opportunities.

Maria Lives

"I'm getting married!" gushed Maria. "He's the most handsome man I've ever met, he loves me to distraction, and why would we possibly want to wait? With both of our medical histories, this is the best time of our lives to commit. Will you stand up for me in our ceremony?"

Well, somewhere between elation for my friend and skepticism about the plan in general, I managed to say something supportive and even enthusiastic. Of course I'd be there for her. I was a friend and one of her team members, wasn't I? Then I realized that a third part of my response was jealousy. I'd have to share her with someone else. My jealousy was followed by a sense of relief: I would share what sometimes felt like a burden. I struggled to balance all four reactions and emotions before finding equilibrium that felt comfortable.

Eight years before, Maria had received a heart-breaking diagnosis and was given six months to live. I had walked with Maria as she faced crisis after crisis, I had struggled to help her create positive ways to live her life as her capabilities decreased and medical issues mounted. I had varied my role in her caregiving with the changing scenarios, and I'd found ways to continue my commitment. Could I do it again this time? Did I want to?

I determined that I did want to stay in Maria's life. I sought professional counseling to sort it all out, and as I did, the answer became clear. I'd have to give up some of my role as best friend, confidant, and caregiver in favor of a simpler and more reciprocal friendship. Care-share team meetings—which once included eight or nine people—came down to only Maria, her case manager, and me. The meetings took a backseat to getting together for coffee and impromptu walks. It took some getting used to, but this was the beginning of a sweet time for Maria, her new husband, and me. After all, Maria had gotten stronger. She was capable of more flexibility and mutuality. And though her illness had progressed, she'd simultaneously grown healthier—focusing less on lesions and more on the world outside of her. As for me, I'd had to give up being the one who always gave. And until the day when Maria may again need more from me, I'll enjoy this freedom and the expanded friendship it's allowed.

Endings and Beginnings

Lives change, and every change involves both a beginning and an ending. Not all persons who think they will be able to participate can do so, and not all can do so for the life of the team. It's important to value all that transpired and all the effort put forth no matter the outcome—whether a care partner recovers or dies, or whether a team member chooses to leave or is fired. Sometimes the current reality causes us to want to rewrite history to either sanitize or satirize the situation. But as Will Rogers said, "Never let yesterday use up too much of today." Once you've acknowledged, respected, and let go of the past, it's important to move on. Talk with other team members about honoring each other's contributions as you go along and marking departures as they happen. It's important to say good-bye, to take time for some sort of ritual, and to allow emotional space for grieving—even if the changes are "for the good."

Reinhold Niebuhr has said, with great wisdom: "Give me the serenity to accept what cannot be changed. Give me the courage to change what can be changed. And give me the wisdom to know one from the other." You can be certain that change will come. You know you can't control it. Thinking through how you'll acknowledge the past and address the future will help you maintain a positive balance and attitude.

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Large or small, losses are often accompanied by strong emotions that may challenge your emotional stability and your sense of self, whether you are the care partner or a care-team member walking beside him. In the following story, John tells of his journey with Deborah, whose good-bye rituals eased her losses.

Deborah's Many Good-Byes

The human resources director at her company initially requested my professional assistance in Deborah's case. She was a professional in her late forties who had early-onset Alzheimer's-type dementia and could no longer function in her important capacity at her firm.

Because Deborah had no living relatives but many friends, I suggested to the human resources director that we help Deborah create a care-share team. She agreed and hired me to set up and mentor the team of friends and co-workers, who worked together for what ended up being a five-year journey.

Deborah's close friend and colleague stepped up to serve as team coordinator. This heroic friend, along with other team members, bravely walked with Deborah as Alzheimer's gradually erased her knowledge, memories, and many skills and abilities.

For Deborah, there were many good-byes: First, her job. Her colleagues donated sick days and vacation time as a gift to Deborah. They invited her to lunch during those weeks when she no longer "worked" but still "dropped by." They hosted a big party to mark her "early retirement" (as they chose to call it).

In the next three months, she said good-bye to her car and her driver's license. She reluctantly gave up paying her bills and managing her health-care appointments, and eventually moved out of her home. Each of these good-byes was accompanied by another ritual to help her grieve what she must leave behind and hand off to her team the tasks that would lighten her load.

Next came the need for twenty-four-hour supervision and a move into an assisted living home. That's where her care team hosted a final party in her honor. When Deborah lost her ability to recognize most of the members of her team, most felt it was more than they could bear and withdrew from the team.

Deborah's last move was into a nursing home, where a structured and protective environment and caring, specialized staff safeguarded her. Only a couple of team members, the nursing home staff, and I supported the remainder of Deborah's journey.

Deborah's story is both heartbreaking and encouraging. Although her team members were saddened by Deborah's losses, they also were forever changed by the enriching experience, the camaraderie, the knowledge of the difference they made, and what they learned about themselves and the other members of the team. Creating and participating in rituals to ease her transitions also helped all of them become more aware of their own emotions. Looking forward to what was next helped them discover the positive aspects of walking through a difficult passage. Several people later told us stories of other teams they helped form thereafter. You've read some of those stories.

Another kind of gift was bestowed unknowingly to a friend, who tells the next story. The gift came through Martha's ability, even as she was dying, to remain curious about new ideas—and to then let her friend know that an idea had taken hold.

Martha's Gift to Her Friends

The greatest gift I received from Martha came about a month before she died. In a phone message, she acknowledged that she never would have believed that what I had once said could be true in her life. During the course of her illness, she'd been profoundly uncomfortable with friends coming together. Yet an unexpected event caused her to reconsider. Two friends had accidentally come to visit her in the hospital at the same time. They met at her bedside, and as they were chatting they discovered a common bond: Both of their daughters were soon going off to college. The surprise for me was Martha's acknowledging delight in hearing them chat about this shared wonder and challenge. I like to think that her final days were eased knowing that her friends had one



another. It was, at last, not just a collection of friends, but a team.

Saying Good-Bye to Team Members

Good-bye rituals are not only important for care partners, but they're also helpful for team members. Having a ritual of sorts for saying good-bye to team members who are leaving honors their good work and commitment, as well as the relationship you've formed with them. The idea is to arrange a formal good-bye for the one who is leaving regardless of the circumstances of their departure, whether it's an out-of-town move, a schedule conflict, or a health crisis.

Vivian Needed to End Care-Sharing Team Membership

Vivian had been a member of the care-sharing team helping Joan care for her husband, Wayne, who had Alzheimer's. As Wayne's dementia grew worse, caring for him was beginning to remind Vivian of her dark, lonely days caring for her father. She realized she needed more time to heal from the long, hard journey of her dad's illness. She wanted to help her dear friends Wayne and Joan, but knew in her heart she couldn't continue as part of the team.

Joan had anticipated that some friends and family members would eventually drop out, so she had recruited an extra large care-sharing team. When Vivian spoke of her need to leave, Joan gathered this team together and suggested hosting a potluck party to celebrate and thank her friend. Vivian at first refused, saying she felt like a quitter and didn't deserve a party. But Joan reminded Vivian that she had already contributed an important, lasting gift—and for that Joan would be forever grateful.

At Joan's request, I, her pastor, retold one of Mother Theresa's stories. Mother Theresa was originally partnered with another sister who was scheduled to travel to India with her, but at the last moment the sister suffered a health crisis and could not go. This sister, however, agreed to be Mother Theresa's "spiritual partner." And while she could not give hands-on care, she could still be of great value to Mother Theresa. Joan asked Vivian if she would pray for her and be her "spiritual partner." Vivian, through tearful eyes, agreed, gave up her guilt feelings, and went on to enjoy the rest of the celebration—her celebration—as her hands-on caregiving for Wayne ended and her spiritual support of Joan began.

Leaving under Rocky Circumstances

Some family conflicts or personal styles may so offend a team member that he or she quits in anger. If care-team members feel they can no longer support the situation, then leaving the group is the most responsible decision.

Care Team Disaster

They both believed their mom needed more help than they could provide and set about asking for help. Unfortunately they couldn't agree on what was needed and who should provide it. And as is sometimes the case with sisters, they were competitive with each other. One of the ways this came out was in each one questioning what the other sister did for their mother. They also disagreed over their mom's level of functioning, how compromised her memory was, and if she was depressed. Professional health-care providers, friends, and other family who wanted and tried to help were frustrated by the conflicting messages and requests. Several paid in-home caregivers finally quit. A couple of friends stopped helping. In time, fewer and fewer people were willing to deal with the frustrations and misunderstandings that the sisters created. Both they and their mother suffered.

Care-team members should prepare for the possibility that the care partner may fire one or several of them, due to personality conflicts, differences in opinions, unprofessional conduct, or concerns regarding reliability. Whatever the reason, whether it seems fair or not, the care partner has the right to do this. If it becomes necessary to say good-bye, developing and following a protocol for leave taking will be helpful.



When the Care Partner Recovers

Good-byes may also be necessary if your care partner gets well, and the care-share team is no longer needed in its current form. This was true for Maria in the first story of this chapter, as well as for Martin in the story below.

Martin Comes Full Circle

When Martin came to Seattle he was ill, alone, and tired. He joined a church that matched him with a faith-based group of individuals who welcomed Martin as their care partner, supplying him with weekly dinners, occasional movie and popcorn nights, and a lot of listening. Over several months, Martin came to trust this group of newfound friends. He came out of his shell enough to confide in them. He was surprised when they became closer, rather than draw away or try to change him.

Martin's health began to improve as he settled into a more stable life, took his medications regularly, ate, and began to have the energy to exercise a little. He began to express his gratitude to his team for their generosity. Then, one week he surprised his care-share team members by cooking dinner for them.

A while later, Martin surprised everyone again when he joined a team that would support someone else who needed a safety net. He said this was his opportunity to pay forward all the goodness he had received. Martin had come full circle.

When the Care Partner Dies

When someone close to you passes on, you'll most likely move through a range of feelings. You may ponder the awe, wonder, and mystery of life. You may feel angry or unsettled as you're reminded that life is fragile, and precious. It does indeed, at just one moment in time, stop. The suddenness and decisiveness of the moment of death may leave you feeling powerless. Even thoughtful preparation is likely to leave you surprised or touched in unexpected ways.

Good-Bye Dad: I Love You

David and I, his counselor, had talked a great deal about what it might be like if he were with his dad when his dad actually passed on. David had believed he was psychologically prepared, but now he wasn't so sure. His father's breathing was slow, loud, and raspy, and his eyes didn't appear to be seeing anything.

David realized that his own breathing was synchronized with his dad's. "We've always been close," David thought. Tears welled up in his eyes as, once again, a wave of sadness washed over him. He reached over onto the bed where his father lay and took his hand. It felt weak and bony and frail but David was, nonetheless, glad to hold it. He was thankful for these past few days with his father and, in a way that surprised him, for the opportunity to touch his dad and hold his hand. While a loving family, they had not been very physical in their display of caring. David sat quietly for a moment as thoughts of growing up and years past swept through his mind. Suddenly, pulled back from his reflections, David realized his father had silently, gently passed on. Tears streamed down his cheeks as he sat marveling at the mystery of life. David waited a few minutes longer, still holding his father's hand, and let memories and feeling float past. Finally, once again with gratitude for all his father and family had shared, David squeezed his father's hand for the last time and whispered, "Good-bye Dad, I love you."

It may also be that, though you are prepared for the death, there are other surprises waiting as funeral arrangements and rituals of leave taking arise.

Sam's Story: A Clash of Cultures and Rituals

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Sam had developed dementia in his late fifties, which was not uncommon for someone born with Down's syndrome. His frail, elderly parents visited almost daily whenever health permitted, but two years earlier they had entrusted his full-time care to the staff of an adult family home. Sam's good nature had quickly won the hearts of the staff despite his limited use of language. The staff members themselves came from five different countries and spoke limited English.

When Sam died, the staff needed a "debriefing" because of their cultural diversity and differing attitudes toward and rituals around death. One staff member reported that in her culture it was a deep honor and show of love to bathe and carefully dress the person who had just passed on. Another warned that, in her culture, only family members could be allowed to look at the deceased person. Another staff member commented that no one was to touch or move the deceased until a spiritual person or a person of God had been allowed to help the spirit leave the body. Another staff person, one who had resided in this country longer, felt strongly that no one should act until the family of the deceased arrived to make a decision.

Despite—perhaps even because of—the fact that Sam's caregivers came from different cultures and held diverse views of death, Sam's story still had a good ending. Sam's parents came in to make the needed decisions and with sensitivity reassured the staff that all was okay. They invited the staff to join them in a celebration of Sam's life and explained that this was part of their family's practice. Everyone agreed to do so.

Sometimes the care partner knows that death is near. When a person expresses that he is ready to go, as Carl did in the story below, saying good-bye may be comfortable and the passing easy. His daughter, Pastor Catherine Fransson, tells this story in what she called a "spirit stone."

Rest in Peace

His desk calendar was at Monday, August 8. On Wednesday the 10th, the nursing staff administered a small dose of morphine to allay his growing anxiety. Hospice had been agreed to, but he had met only one or two of their staff. Thursday when he walked fully dressed, walker-in-hand, to his shower, he told the aide, Debbie, he was dying. She told him she loved him, and he said I love you, too. They hugged. And at 2 a.m. on Friday, August 12, they found him in his small bed, still, his face calm. No extraordinary measures were ordered.

Five weeks after his 101st birthday, Carl Abner stepped out of this dimension and embarked on a new adventure.

I meet the nurses who saw Dad through. I hear the stories of his final hours and days. There are tears in their eyes as well as mine; they cared for him, loved him over the three and a half years this was his home: a good home, a place of caring and respect, of enough space for the way he needed to live his life, and of not a little joy.

Who would have thought my father's move to a nursing home would become such a gift in so many ways? His relinquishing the authority he'd wielded all his life. His relaxing into the routine. His comfort at being left alone. The freedom to do whatever he chose within the constraints of the place. He read the Wilson Quarterly, two newspapers, two news magazines, and the dictionary, always delighted to discover new meanings.

Here I discovered his deep shyness, his inability to hold two ideas in juxtaposition, his inability to imagine another scenario from the reality he experienced; and his great loyalty to my mother, his deep faith, his graciousness for all those who helped him through the day, and his gratefulness for my own regular weekly appearance at his side, listening, responding, asking questions, and—may I be frank?—getting acquainted.

His pastor once said of him, I have never met such a Lutheran conscience. I am not sure what that means, but I think it's a left-handed compliment. Maybe that's all the compliment any of us gets: an admiring on-looker, envious of the iron will, the constitution, and the sense of humor that gets any of us from 1904 to 2005, or 1942 to 2043, when I will reach his age.

My dad will rest in peace; he would have nothing less.

—Blessings from Catherine Fransson, August 19, 2005



In contrast to Carl Abner's story, in Ginny's case, all agreed that she died "before her time." The team members all knew months in advance that she was dying, and individually and collectively they had dealt with the anger, unfairness, and diverse other feelings that arise when a young person dies. Thus, having done this emotional work toward acceptance, the team was better able to celebrate the joy of Ginny's life at her memorial service.

A Celebration of Ginny's Life

Ginny was a brilliant scholar who, at age thirty-eight, developed a cancer in her brain. For eleven months, friends and family formed a close care-share team and partnered with Hospice to help Ginny pass on amid love and care.

The ceremony was held in a small interdenominational church. Pictures of Ginny surrounded the pews. All who attended, including the care-share team members, had been invited to bring memories to share. During the three-hour service, there was much grieving, crying, a lot of laughter, and joy as memories were shared. The care-team members were so touched by the ceremony that they decided to gather one year later to again celebrate Ginny's life.

Grief 101

A Cut Finger

Is numb before it bleeds,
t bleeds before it hurts,
It hurts until it begins to heal,
It forms a scab and itches until finally, the scab is gone
And a small scar is left where once there was a wound.
Grief is the deepest wound you have ever had.
Like a cut finger, it goes through stages and leaves a scar.

— Author Unknown

Care partners may grieve at different times—and in different ways—than their care team. Being part of a care team gives you multiple opportunities to become knowledgeable about grief and to become a good griever. In small and large ways, life demands that we grieve our losses, harvest our memories, and move on. Even "positive" changes—a new job, a move, a marriage, a birth—involve losses. The old job, the house left behind, a more complex or a more carefree life are gone. The euphoria of the positive is often balanced with an unrecognized sense of loss. With this may come confusion. Simply noticing this will help you manage that emotion. What's more, there are many valuable books, articles, Web sites, grief counselors, and other resources focusing on understanding, experiencing, and eventually passing through grief. As you learn to recognize complex emotions, you will become better prepared for the time when you encounter a huge loss.

Ezra Makes Peace with His Grief and Anger

Ezra told me he had been born in the Midwest into a family with nothing. Through extreme hard work and self-sacrifice they become moderately successful. Unfortunately for young Ezra, there was far too little time and attention for this sensitive and intellectually gifted boy. Additionally, his father, who was raised in Europe during very difficult times, was harsh in word and action with Ezra.

As his father aged, Ezra was forced into a caregiving role for this frail and difficult man. In my consulting and counseling with Ezra, a complex picture emerged. Ezra felt a deep mixture of anger and grief over all he had missed, over some of the ways he had been treated, and over what he had hoped to receive from his father before he died. As he sorted out these emotions and fully experienced his feelings, Ezra slowly came to make peace with it all and found that his caregiving time with his difficult father became a little easier. Ezra also discovered meaning and significance in the many ways he had been different from his father in parenting his own two sons. Ezra also reported feeling more open and expressive with family and friends.

The "up-close time" that illness brings can give you a new awareness and understandings of yourself and others.

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Both healing and renewed growth can be a valuable part of your journey forward.

Everything in this life comes to an end. Even when the care team you form ends, you can expand your understanding of complex emotions. Consider the following:

- You quit the care-share team, perhaps because you can no longer commit the time, you move, or you are burnt out. You likely will feel relief, guilt, fear for the care partner, or adrift from the team, who've supported you emotionally.
- The care partner dies, and the team dissolves or decides to meet annually to commemorate the passing. You may feel grief, anger, or gratitude for the time you spent helping and for the camaraderie of the team.
- The care partner gets better and no longer needs help. You may feel glad for the care partner, but sad to say good-bye to the team. You may feel equally happy you no longer have to deal with team complexities.
- The care partner dismisses everyone, and you experience anger and relief.

Whatever the reason for the team ending, you likely will experience complex feelings: relief mixed with sorrow, anger combined with guilt, or fear overlaid with depression. All of this is normal and needs to be accepted, experienced, understood, and passed through to the other side. What's important to remember is that with loss comes grief. Grieving is necessary for healing and moving on.

The Grief Process

When the team ends, especially when the care partner dies, each member of the team will experience some form of grief. To resolve and move through your grief, it's helpful to understand Elizabeth Kubler-Ross's spiral grief model. Unresolved grief comes from trying to jump from one side of the cycle to the other without acknowledging and experiencing all of your feelings. Not everyone will experience these feelings in the same order, but most people experience most of these emotions at some point during loss and change. Typically the emotions come and go.

Especially for some men, the grief process may be quite difficult, often because it is denied. Most men have learned from a very early age to control and often hide or suppress their feelings. Men often learn these lessons so well that they develop deep, usually no longer conscious, habits of not showing or not even feeling their sorrow, fear, and loneliness. Interestingly, we have observed that sometime around age fifty, men lose the ability to "rise above" or "sidestep" these feelings and must relearn how to grieve, to experience the feelings Kubler-Ross describes. This actually helps them to eventually heal and move on.

There are many ways we experience grief. Grief can show up as fear, anger, or emotional withdrawal. Some people have a way of shedding tears internally without showing a single drop on the outside. Thus, many of us must counter strong anti-grieving learning while trying to learn how to grieve and mourn. We urge you to get to know your ways of grieving, to learn to grieve, and to let grief pass through you as do the other emotions.

Gifted grief counselor Bonnie Genevay has compiled this list of "ways of grieving" to help people begin to make a space for, or practice, grieving:

- Writing (journal, diary, poetry, letter to a friend, or letter to the lost one).
- Talking about the loss, expressing feelings (with a friend, with a family member, in a grief support group, with a counselor).
- Walking (allowing nature to bring forth memories, feelings); running.
- Sitting with a person who knows of your grief, not talking but sharing the silence.
- Crying; joining others as they cry.
- Slowing down in behavior and thought so that the meaning of the loss can surface and you can understand the depth of loss.
- Raging; allowing the anger inherent in grief to emerge through words or the voice (i.e., cussing in your car on the freeway).
- Touching (holding hands, holding someone else who shares the grief, hugging/being hugged all elicit feelings of grief).



- Throwing rocks in a stream.
- Listening to music.
- Painting, drawing, creating art.

-- Bonnie Genevay

Cycles of Loss

It's strange that anyone could make any sense out of the confusing and changing constellation of feelings, thoughts, actions, physical sensations, and social changes that can accompany losses of those we love. But there are common characteristics that have been identified, most notably by Elizabeth Kubler-Ross.

From the time of the loss, you will cycle through shock, denial, anger, and guilt; bargaining, fear, and tears; despair and depression; and resignation, adjustment, and acceptance before reaching a point that can be called recovery. You may find yourself frequently returning several times (and in no predictable order) to steps you've visited before. Not everyone will experience all of these steps, and they won't come in predictable order. The above list is very general, but has been tested and is generally true. Trying to jump from loss to recovery without acknowledging feelings or taking time for them frequently results in unresolved and complicated grief reactions, frequently leading to depression.

The cycle of loss never truly closes, because experiencing the loss and its grief changes you forever. How you are changed depends on your own attitude and determination. New depth of character and strength may emerge. Bitterness, anger, and withdrawal are the other end of a spectrum, with many variations in between.

In addition, with each new loss you face, emotions connected to prior losses are likely to surface, and you may encounter these leftover emotions yet again. Feelings of shock, numbness, self-reproach, sadness, hysteria, vulnerability, relief, craziness, or fear are not at all unusual. Their intensity may be unexpected, and there may be big swings from one to another. Similarly, physical sensations may be surprising. Headaches, shortness of breath, lack of energy, excess nervous energy, hypersensitivity to noise, dry mouth, hot or cold flashes, stomach upsets, clumsiness, or tightness in the chest may come and go.

At times you may encounter sensations that seem completely unreal. You may be preoccupied, forgetful, confused, or unable to concentrate or remember. These reactions are all normal. You may sense that you're seeing, hearing, or feeling the one who has died; you may even have thoughts of ending your own life.

Again, most of these feelings, sensations, and thoughts are normal. They are passing, though the length of time they last is difficult to predict. You may suffer recurring bouts of sleeplessness or feel absent-minded. At times you may seek solitude or want the company of others. As you move through the grief process, you may also experience changes in dreams, changes in sexual activities, marital difficulties, anxiety, or the unwelcome feeling that you are different from those around you. Again, these experiences are fairly normal and part of the cycle. They will not last forever, but if you're experiencing one or more and are concerned, you can take action. First, start noting on a calendar whenever the disturbing thought, feeling, or action occurs. Track this over, say, three months. This will provide valuable input. Next, you could keep a journal, which will give you the same kind of data as the calendar, with more emotional detail. Or seek professional counseling. Our experience tells us that the first two steps often eliminate the need for the third. (While a fleeting thought of ending your life is normal, if you find yourself seriously considering ending your life, please call a crisis hot line for help.)

If, however, you can treat yourself gently, stay with the feelings a little while, and trust that you are not alone in feeling this way (people over the millennia have encountered the same grief process), these unusual intruders will soften and diminish. "I can't stand it" may slowly become "I'm prepared to move on."

Helping Someone Who is Grieving

If you know someone who is grieving, you may worry about saying or doing the wrong thing. When you are thinking about what to say to someone who is facing a loss, reflect upon your own grief experiences—what words and actions comforted you? Here are a few simple suggestions from people in grief about expressions that were helpful

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and those that were hurtful.

Things That Hurt

- Being avoided: People didn't know what to say or do; they avoided talking with me. They were uncomfortable, but it made me feel isolated.
- Being pushed to talk: Sometimes I didn't feel like talking, and sometimes people were nosey and kept asking what was wrong. A gentle knock at the door is what I welcomed—then, I could talk, or not.
- Being told how to feel: I was told I should cry or I shouldn't cry. I shouldn't be angry. I should feel better by now. People assume I should feel a certain way because "everyone feels that way." My feelings are my own, not right or wrong, they are just what I feel. There are no rules for grieving.

Things That Helped

- What meant the most was knowing that people were thinking of me and that they cared.
- Helping others: When I helped other people, it made me feel better. It took my attention away from my grief.
- Talking: When I felt like talking, I was grateful to friends who weren't afraid to listen and share.
- Laughing: I also learned that it wasn't wrong to laugh and have a good time. Laughing gave me the same kind of relief that crying did.
- Hugging/affection: A hug from a friend often made me happier than any words a friend could say.
- Being with friends: I liked it when my friends asked me to do things with them in the same old normal ways. I liked it when they came to the house and also when they took me away from the house.

We've included the lists above to help you think about how to comfort a grieving person and how to be more at home with personal grief. Grief can indeed "wash us larger," that is, deep experiences can leave us with greater inner and relational capacities. Being reminded of this fragility and passing nature of life—cherishing what has been and savoring what's ahead—are gifts that, though difficult and uncomfortable, have value.

Children Grieve, Too

While an in-depth discussion is beyond the scope of this book, we must point out that children grieve, too. Many excellent resources are listed in the Bibliography and Resources sections in the back of the book. Whether a child is ill, exposed to divorce, or missing the time and attention that must now be given to addressing significant life changes, he will need to express his grief. Care-share teams can include older children in the care plan to help fill the gaps left by a parent or sibling who is ill or emotionally unavailable. What's more, one of the many joys that may come from team participation is spending time with a child and playing an important role in her ongoing growth and development. She benefits by participating—and so does the rest of the team.

Grieving is a child's normal and healthy response when someone in his or her life is ill, is no longer the same, or has changed. Every child has an innate ability to heal. Like an adult, each child grieves in her own unique way. The way to assist a child's grieving process is to give truthful information, listen carefully, and provide acceptance, caring, and a lot of love.

Marking endings and losses as well as beginnings, through ritual and ceremony, is an opportunity for the community to come together, share, and grow more solid and to note and celebrate what has been done. We've just scratched the surface of this important topic and urge you to learn all you can about how to survive and even thrive during life's inevitable losses and endings.

Get Ready

Talk with the group: What will you do if someone decides to leave?

Pay attention: What are the little things that the care partner is losing?



Think: How do you deal with good-byes and endings? What do you need to do to be better prepared? Do it.

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