

## Conversations with the Experts

### Sibling Dynamics and Elder Caregiving



**Francine Russo**

**Bio:** Francine Russo is the author of the new book, *They're Your Parents, Too! How Siblings Can Survive Their Parents' Aging Without Driving Each Other Crazy* (Bantam, 2010). Dr. Russo is a widely-recognized journalist known for her alertness to developing trends, especially in her own boomer generation. Keenly attuned to psychological themes, she has honed the intimate interview, encouraging her subjects to discover and articulate their own deepest feelings. For nearly a decade Dr. Russo covered the boomer and aging beat for *Time* magazine. Her pieces for *The Atlantic* sparked media debate and were widely anthologized. She has also written for *The New York Times Magazine*, *Redbook*, *Family Circle*, and *The Village Voice*. In 2009 she became a *New York Times* Fellow at the International Longevity Center. She has a Ph.D. in English and lives in Manhattan. Since the publication of her book, she has been in demand as a keynote speaker.

#### An Interview with Francine Russo by Julie Weber and Mary Curlew

**Weber:** How did you first become interested in the topic of how siblings interact when their parent's health is declining?

**Russo:** As often happens, I became aware of it first in my own family. I'm one of the oldest of the boomers, and so what happens to boomers tends to happen to me first. As a journalist, that's how I got to cover the boomer beat. In my family, I was the far-away, uninvolved sibling. My sister lived near my parents, and when my mom was failing, she was helping my dad. There were some uncomfortable family dynamics: lots of anger and guilt. I would call on Sundays and go down to visit, but I kept my distance because my mom was pretty judgmental and not so loving. My younger sister, it seemed to me, had been angry at me from the day she was born. Also, my dad was sweet but took whatever my mom dished out. Hard to be around. So as my mother was failing and my sister was helping my dad, no one asked me to help, and I didn't volunteer. It wasn't until I saw my father and my sister clinging to each other and weeping at my mother's funeral that I finally got it. They had been through this horrible ordeal without any support from me. I felt deeply ashamed, and I did a lot of soul-searching. Really, I am not a terrible person. So how did I get this so wrong? Eventually I would apologize to my sister, but I also learned to forgive myself. Because what happened in my family—what happens in everybody's family—is very complicated and way bigger than one person's mistakes.

In my reporting for *Time* magazine, I saw that so many siblings were in similar trouble, fuming or fighting. My sister and I were caught in what I call the "anger-guilt gridlock." She would say, "You never come," rather than "Would you help me?" She would try to make me feel guilty—which was a long tradition in my family—and I would respond by withdrawing, which was my life-long response to my family's imposition of guilt. My sister just got angrier and angrier, and the more she tried to make me feel guilty, the more I withdrew. This is a very common pattern in families.

**Curlew:** What made you decide to write a book on this subject?

**Russo:** I was covering the boomer beat for *Time* magazine, and people were writing to me at my column, "Ask Francine," where I also covered some caregiver issues. I discovered that more and more people were having difficulty with their siblings, and I concluded, "This is a story!" I hadn't seen this story anywhere. So I started

reporting on the story, talking to lots of experts as well as many siblings. I found out that in these complicated family situations, the revival of sibling rivalry over aging parents is very common and quite intense. I also found, as I looked into it, that this situation was a huge and complex topic, much bigger than what I could cover in an article. I then knew it was going to be a book—my first book. The subject was a new family transition in the life of the original family, in which siblings have to interact intensely again with each other and their parents. Yet almost nobody was talking about it. Nobody was studying it in-depth.

**Weber:** How have changes in today's families brought caregiving and elder-care issues into the spotlight?

**Russo:** Of course, you know about the longevity revolution and how people today are living 30 years longer than they were a century ago. What's also true is that, because of the miracles of modern science, our parents are living not just longer, but for perhaps a decade with chronic illnesses that at another point in time they would have died from. Living with chronic illnesses, they need more and more help. It's a kind of perfect demographic storm. At the same time that our parents are living longer, the various revolutions of the 20th century—the women's revolution, the mobility of the population, and the changes in family structure—mean that brothers and sisters are living far from their parents and far from each other. Women are in the workforce and are not available for caregiving. So just when there is a greater need for care, there are fewer available caregivers.

Never before have siblings had to experience this long family reunion, where they may have to reengage for 5, 7, or even 10 years over the needs of their aging parents. That's just never happened before. Think about those funny Hollywood movies that come out every Christmas about getting together for the holidays, with everyone acting the way they did when they were 10. However, instead of siblings going away at the end of the weekend, it just goes on and on and on. Instead of arguing about who is doing the dishes, you're arguing about major commitments of time, profound family relationships, and ultimately, life and death issues. It is very, very challenging.

**Curlew:** You use the term "twilight family" in your book. What does that mean?

**Russo:** There are many kinds of family transitions that family therapists and psychologists have studied. The first family transition is the couple getting married and forming a family. Then they have a child, and that is a major transition. When the children reach adolescence or leave the nest, that is another major transition. Anxiety is almost always present, and we have conflicting feelings about moving on to the next stage and giving up some aspect of the status quo. So, let's say we have a family, and our kids are leaving the nest. How terrible, how wonderful! It can arouse deep and unsettling emotions. What nobody has ever studied before—because it has never happened before—is what happens when the *original* family has to get together again at the end of the parent's life. It has never been studied, yet it is a major, new family transition. I call it the "twilight" because it is the twilight of the family in which we grew up. It covers that long period of the decline of our parents and the formation of what will be our family in the future, where the adult siblings will be the leaders and the oldest generation.

This is a major emotional passage for the family and for each individual in the family. For the family, family systems theory has taught us how people take on complex roles in the family, which are not always transparent to us. When we re-engage after decades, these interconnected roles no longer work well because some of the original family members may be missing, and everyone is changed.

All of this is very, very challenging. If this were not stressful enough, each of us individually is experiencing a major psychological crisis: confronting the decline and loss of our parents, and right behind that, our own mortality. That is pretty scary stuff, and it awakens some old and deep needs: needs we have from our parents, to be loved a certain way, to be judged as being "okay," or to be loved as well as a sister or brother. These needs come up, and we are often not aware of them, but they color all of our interactions at this time. That's why sibling interactions can become incredibly explosive, especially if people are not conscious of these feelings.

**Weber:** What would you say are the biggest pitfalls to be avoided by siblings who have an aging or ailing parent?

**Russo:** First, people do not plan ahead, either practically or emotionally, for the aging of their parents, and instead wait for a crisis. So many people have said to me, “I was not prepared for the feelings.” So, it is my hope that my book will help people be aware of what is coming, and that people will start to talk about it—before there is a crisis: “Okay, we are all in different places, if this happens, and mom dies first, or if dad dies first, and mom needs care (which is the typical situation), where will we each be? Is there a way for us each to contribute? It is probably likely, since I live closest, I will take the major role. But what will each of you be willing to do?” I also hope this book helps people become aware of ways in which the caregiving can be undertaken somewhat jointly, although it is rarely equally apportioned.

The second pitfall is falling into our old roles automatically without examining or adapting them.

The third is fighting old sibling rivalries without realizing it. For example, if you and your sister are having an argument over whether mom should hire a home health aide or whether she is fine the way she is, you may find the argument becoming explosive. You may start thinking, “She doesn’t care about Mom,” or “She doesn’t care if Mom falls and dies.” If the conversation gets to that level, that is a clue that you are fighting not just about hiring an aide. Instead, you are fighting about which of us understands mom best, which of us cares about her most, which of us will be loved by her most. That is a clue to step back and really examine your own feelings, because that awareness can make a huge difference in sibling interactions.

A fourth pitfall is thinking that caregiving is a merely a job, and if one person does it, then the other sibling is off the hook. This can leave the caregiver feeling alone, abandoned, and angry. Another pitfall on the caregivers’ part, is not being able to identify what they need help with and not being able to ask for it in a way that will be effective. These are all major challenges.

**Curlew:** Are there any particular difficulties, both emotional and financial, faced by siblings who have a parent who is suffering from dementia?

**Russo:** Definitely. On a practical level, dementia requires many more years of caregiving and more demanding care. In fact, by the end of the life of a parent with dementia, caregiving may be required 24/7. This kind of job is too big for any one person, especially an employee/caregiver. It may require a team effort on the part of the siblings, having a parent move into a facility, or having a 24/7 home health aid. Whatever the solutions, the financial burdens can be astonishing; families can be driven to the brink.

On the emotional level, adult children are experiencing what Pauline Boss, a well-known family therapist, has described as “ambiguous loss.” This is a very special emotional challenge with any kind of dementia, where children often feel that their parents are both here yet not here. The resulting ambiguity is very hard for people. We live in a culture that values certainty. It is right, it is wrong; it is black, it is white. The way we tend to deal with the uncertainty is to make a decision on one side or the other. If you are the caregiver, you may say to yourself, “Mom has not said my name in 3 years, but I see that light go on in her eyes when I walk in the room, and I know she is there.” On the other hand, your sister may say, “Mom checked out long ago. It is really painful for me to be near her.” The siblings may get angry at each other’s positions and find themselves unable to support each other. However, Pauline Boss teaches that all of these positions are to be respected. There is no right or wrong position. Indeed, if the siblings can be respectful of each other’s feelings, they can often find ways to work together and be supportive.

**Weber:** How does caregiving stress surface at work for employees and supervisors?

**Russo:** A lot of this stress has been well documented. You can read in MetLife’s study and other studies that there are constant emergencies and anxieties, resulting in a lack of focus on the job. Absenteeism and retention are major problems. Still, what is less well known is how the stress of the sibling relationship adds to this. There are a couple of interesting sociological studies that are relevant here. Sociologists Sutor and Pillemer did a study of married caregiving daughters. They found that their biggest source of interpersonal stress was their siblings. More recently, sociologists Ingersoll-Dayton and colleagues did a study of caregivers and found that even though the researchers did not ask the caregivers a single question about their siblings, their feelings about their siblings erupted spontaneously. This led the team to conduct a second study to examine sibling issues.

In this second study, they found a great deal of what I call in my book the “anger-guilt gridlock.” When the sibling caregiver makes the others feel guilty, they defend themselves against guilt in a variety of ways: by rationalizing, withdrawing, getting angry, or minimizing what the caregiver does. This leads caregivers to feel abandoned and lonely and without emotional support from their siblings. These feelings may be further exacerbated by a workplace environment that employees feel is not truly supportive. If caregivers already feel abandoned and alone, and if they feel they have to hide their needs in their workplace or do not feel fully supported, that’s bound to make them less involved and productive.

**Curlew:** What supports can employers provide for employees living with this twilight family situation?

**Russo:** First of all, I would endorse the recommendations from DARTS in St. Paul, Minnesota, a nonprofit that helps seniors and their families. DARTS created the workplace elder care seminars that won last year’s National Family Caregiving Award. They strongly recommend workplace education: a brown bag lunch hour program to educate employees on work/life issues, provide access to experts in aging and caregiver services, or provide access to a library of caregiving resources.

I would add to this: sibling stress is so prevalent that employers could also provide either access or referrals to psychologically trained professionals—including geriatric care managers, social workers, and family therapists—who work with twilight families every day. These geriatric professionals can sit down with the siblings or arrange conference calls to facilitate better communication and distribution of tasks. Cutting through any emotional distortion, anger, or guilt of the involved family members, a good geriatric care manager can call a family meeting or conference call and say, “Okay, here are the facts about your mom’s condition. This is most likely what is going to happen in the future. This is a list of things that will need to be done for her. It is too big a job for one person, and some things can be done from a distance through technology, or other ways. Which of you can take on these tasks?” This intervention can greatly relieve the employee who has the greatest burden of caregiving.

Also, it would be helpful for employers to provide access to education about respite services and encouragement to use respite services. They can also provide their employees access to books like *They’re Your Parents, Too!* to give them insight into how to improve their relationships with their siblings. If they can get better cooperation, they are likely to feel less stressed.

I just want to say on a personal note that I gave a presentation to caregivers and professionals last week in St. Paul at the DARTS center. Just this morning, I received a note from an attendee, who said: “I am enjoying the book so much. It really opens up what my sisters have felt that I didn’t know they felt. This could heal many families.”

The last suggestion I would make is for employers to offer professionally led caregiver support groups in the workplace.

**Weber:** What further research might be helpful for working families who manage caregiver issues?

**Russo:** I think that it would be useful to have better data through surveys on caregiving: employees’ number of siblings, location, and availability, and the type of support that is being provided by siblings of employees, and what might be provided.

It would also be useful to have research to identify signs that an employee could benefit from family counseling or therapy.

In addition, while some of this may have been done already, it might also be helpful to conduct research on the workplace validation of employee-caregivers. From the beginning of caregiving research, Steven Zarit at Penn State University—one of the pioneering gerontologists—found that the difference between caregivers who could function well and those who were completely devastated by the tasks was not so much the number of hours they had to do it, or how hard the care was. Rather, it was the meaning they personally assigned to their role as

caregiver. Did they feel that it was a worthwhile and important role? This positive meaning may be impacted by whether employees feel their role validated by the workplace, or whether they feel their employers see it as a nuisance. Thus, research further exploring workplace validation of employee-caregivers could be important and useful.

**Curlew:** Can caregiving and elder care issues benefit from public policy initiatives, such as paid family leave or flexible work schedules?

**Russo:** Definitely. First of all, I want to endorse paid family leave and flexible work schedules. I also think that people who are not the main caregivers, the siblings, could also be included in public policy thinking. For example, perhaps there could be tax benefits for the siblings from afar who contribute financially by hiring a home aide, a service that might not be covered under insurance or any other program. This tax benefit could not only help the caregiver with emotional and financial assistance, but it could also help the far-away sibling feel part of the caregiving process.

**Weber:** Do you think there is opportunity for families to reengage in positive ways, even through this is a difficult and emotional passage?

**Russo:** Yes. That's the best news during this difficult passage. There are tremendous opportunities for deep satisfaction, for important personal growth, and for closeness and family connection even with siblings with whom you did not think it would be possible. This strengthened family connection can also sustain employees in the difficult time when they are grieving their parents, and in the years after, as they become the oldest generation of their family.

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E-mail: [wfnetwork@bc.edu](mailto:wfnetwork@bc.edu) - Phone: 617-552-1708 - Fax: 617-552-9202



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