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How Out-of-Towners Stay in the Loop

BY MARC SILVER

The challenges of caregiving from a distance.

Two things were bugging Annette Clark: endometrial cancer and a dirty chandelier in her San Francisco home. Every six weeks or so, devoted daughter Kim Clark would fly in from Maryland to lend support in her mother's battle against cancer and to attend key doctor's appointments. But when Annette asked Kim to clean the bedroom fixture, Kim figured it wasn't such a high priority.

Then Annette's son and daughter-in-law came in from Norway, where they'd been living, for a visit. Annette mentioned the chandelier; the daughter-in-law started cleaning.

"I wasn't listening," Kim says. "Her daughter-in-law was more objective. She listened, and that made my mom happy." For Annette, the dirt on the chandelier was a reminder that coping with cancer made it harder to keep up with household chores. "You don't want to see a downsliding of care in your home," Annette says.



Kim Clark, of Maryland, served as a caregiver for her mother, who lives in California. Photo by Sara Lewkowicz.

Like any caregiver, a faraway family member needs to remember that paying attention to all of the patient's requests is the top item on the job description. But listening from a distance—or during infrequent visits—is a daunting art, as millions of Americans are learning. More than five million U.S. residents are long-distance caregivers, according to data collected by the National Alliance for Caregiving and AARP, a number that's expected to increase significantly in the next 15 years because of the aging (and footloose) population. And while technology can help, it's not a cure-all.

First, a definition of terms is in order. For the purposes of this article, caregiver refers to any close family member who makes an ongoing effort to help. As for long-distance, that's subjective, especially in an era when an hour-plus commute to work each way is fairly common. Yet when Donna Wagner, PhD, director of gerontology at Maryland's Towson University, asks focus groups the amount of distance that separates in-town from long-distance caregivers, they always say it's an hour—just far enough to make a pop-in visit unlikely.

Absence Makes the Heart Grow Frazzled

“The long-distance caregiver is often behind, but needs to be ahead of the game,” says Hester Hill Schnipper, chief of oncology social work at Beth Israel Deaconess Medical Center in Boston. Getting ahead requires asking very specific questions about all sorts of matters. Is getting to doctors' appointments a problem? Is the patient eating enough? Taking all the pills prescribed? And what's the prognosis?

In the best of circumstances, an on-scene family member or friend can brief out-of-towners via phone calls, e-mail blasts, or a personalized website. Still, a long-distance caregiver might want to plan a visit to coincide with initial doctors' appointments. The patient gets an extra pair of ears, the caregiver puts a face to the doctor, and the doctor gets to know the patient's family.

On subsequent visits when decisions about treatment are discussed, an out-of-towner who has taken on an advisory role can ask to be conferenced in on a speaker phone. That's what Kim Clark does. She's frustrated, though, when conversations occur in the phone-less examining room. Julia Bucher, RN, PhD, a nursing professor at York College of Pennsylvania and co-editor of the American Cancer Society's *Complete Guide to Family Caregiving*, proposes the cell phone solution: Make sure the patient has one and knows how to use the speaker option.

Then there's the HIPAA privacy form, a document that both long-distance and up-close caregivers should know about. If the patient signs, the doctor can speak directly about the case to designated family members. So the caregiver can ask questions the patient may not be willing to ask.

If a doctor is hard to reach by phone, a distant caregiver might try making an appointment for a 20-minute call. In any discussion with a doctor or nurse, you don't want to waste time going over basics that can easily be obtained elsewhere. Cancer websites that dangle .org, .edu, or .gov suffixes are more apt to have the most accurate information.

The Electronic Age

New technology certainly makes it easier to keep tabs on a patient. But long-distance caregivers shouldn't assume fancy tools will solve all problems. "The question isn't what technology is available but what are the needs of the person in treatment and the challenges for the caregiver at a distance," says Lazelle Benefield, PhD, RN, a professor in gerontological nursing at the University of Oklahoma Health Sciences Center.

A webcam on the caregiver's computer and the patient's computer is all it takes for videoconferencing. Some computers come equipped with webcams. For others, a pair of cameras cost \$100 or less; the software is built into many e-mail services, including AOL and MSN.

Technology helps in other ways. Health experts are high on web services like Lotsa Helping Hands, which allows local and distant caregivers to coordinate help and share information and stories as well. Monitoring services, such as Lifeline, make it possible for the patient to get fast help in case of a fall. Such services also offer telephones that have programmable reminders to take daily pills.

But human beings can't be replaced by gadgets and gizmos. Depending on the patient's condition, a distant caregiver may need to turn to visiting nurses, home health aides, housekeepers, bookkeepers, and drivers. Services are available that provide and coordinate various health care and support services, with programs that can be customized to a patient's needs. An oncologist's office or a local department of aging should be able to supply a list of providers or volunteers that offer such services.

The hard part may be convincing the patient to sign on. Bucher suggests putting the burden on the long-distance caregiver: "Do it for me—it makes me feel good." She also suggests setting an initial time limit so the patient has control over the situation: "Let's try this for a week or a month and see how it goes."

Actually, Alexander Graham Bell's invention is still an excellent way to bridge physical and emotional distance. A daily check-in call is a good idea, if the patient is game. So is an "appointment" call for longer conversations, factoring in time zone differences and prompting both parties to clear time for a talk with no distractions.

"You have to make sure you're up to it and you're there for them," says Diane Schwartz-Williams, who'd make phone dates with her sister, Carolynn. "Don't sit at your kitchen table with the pot steaming on the stove or at a desk with piles of papers."

Even though Carolynn, who had cervical melanoma, lived in Winnipeg, Canada, and Diane lived two and a half hours away in Kenora, there was a little long-distance phone therapy. "I remember once I could tell she was upset," remembers Diane, "so I said, 'Yell.' I said it five times. I made her yell in the phone. We were laughing, but it's a stress reliever."

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—Lazelle Benefield, PhD, RN

Stressful Times

There will inevitably be times of intense contact for long-distance caregivers, and times when contact wanes. Andy Buerger's sister Jodi was diagnosed with metastatic breast cancer in 2004. She was in Boston; he lived in Baltimore, as did most of the immediate family.

For six months, the family set up a rotation of visits, flying in to help with every-thing from changing diapers on Jodi's new baby to taking her to chemo sessions. Today, Jodi is trying to live her busy life as normally and privately as possible. Andy regrets they only seem to talk a couple of times a month—not as often as he'd like.

“It [was] frustrating to sit here in Baltimore—I [wanted] to climb in that chemo chair and get chemo for her,” he says. Andy channeled his energies into the search for a cure for metastatic disease, raising over \$100,000 for an anti-cancer vaccine being studied at Johns Hopkins University. He established Climb for Hope, a group that runs mountain expeditions. A would-be mountaineer must raise \$9,000 in pledges. “Jodi is appreciative that this fundraising effort is going on because of her,” he says.

Not every family moves forward in harmony. Schnipper recalls a New England widow with a daughter in town and a son on the West Coast. When Mom was diagnosed, the daughter drove her to doctor's appointments, cleaned the house, and fixed meals. The son flew in from time to time; when he'd arrive, Mom would say, “I'm fine, go out and see your friends.” Which he did, much to his sister's annoyance.

The beleaguered sibling's only hope may be to give specific orders, says Schnipper. But family dynamics don't necessarily improve in a crisis, and some caregivers inevitably shoulder a greater burden than others.

Like any sort of caregiving, long-distance support comes with a cost. And it's not just the emotional drain or career sacrifice. It's dollars and cents for plane tickets, housekeepers and health aides, gifts mailed, goods purchased during a visit, and more. A National Alliance for Caregiving survey puts the average annual cost for the long-distance caregiver at around \$9,000. The American Cancer Society can provide information about services, as can hospital social workers.

Some caregivers function better at a distance. When Lisa Boozer in Tennessee was diagnosed with breast cancer, her mom in New Jersey couldn't cope. Brenda Culbert had already lived through a round of radiation for Lisa's teenage battle with Hodgkin's disease.

“I knew I couldn't handle the situation and I knew she had a wonderful network of friends,” Brenda says. Lisa understood completely. “I didn't need to be around

anyone who is crying all the time.”

Lisa’s advice for families who’d like to let a long-distance relative know it’s OK not to visit: “Have a third party, like a husband or friend, talk to her behind the scenes.” Brenda, who sent money to cover medical and travel expenses during treatment, did come once active treatment was over; she also counsels other long-distance moms through the nonprofit group Mothers Supporting Daughters with Breast Cancer.

But who supports the long-distance caregiver? All caregiving is stressful, whether up close or from afar, and all caregivers need to factor in down time. When Diane Schwartz-Williams would make the drive from her home to see Carolynn, she’d put her job out of mind, keep the radio off, and just soak up the silence.

Even the patient can provide support, sometimes in the most unlikely of circumstances. A few weeks after her sister died in 1999, Diane sat on her front porch. She was furious at Carolynn. In her head, she unleashed a mighty yell: “Why did you have to die?” And she made a demand: “If you’re out there in that breeze somewhere, I want a bird to sit down and land right beside me now.” Within four seconds, a whiskey jack alighted next to Diane.

“It made me feel better,” says Diane. Maybe it was a coincidence—or maybe it was a heavenly example of long-distance caregiving.