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Meet the Parents' Caregivers

BY MARC SILVER

Children go from being cared for to giving care.

Mary Overall is an expert juggler. She and her husband have a house to keep up. She works for an Oklahoma City health care group that helps the uninsured. And she is her mother's keeper.

Malinda Hudspeth, 90 years old, fiercely independent, and still living on her own, is battling breast cancer that has spread to the bone. Overall takes her mother to appointments, makes sure she understands medical options, fills her prescriptions, and helps with chores in her mother's home. Each day she's up at 5 a.m. At 7 in the evening, she takes a short break, and then gets busy again. Bedtime is around midnight.

Sometimes after two hours, adrenaline pumps her awake. When she's utterly spent, she'll appeal to a family member: "I've just got to have eight hours of sleep. That'll energize me for the next 60 days. Would you be kind enough to support me with this?"

Mental health experts are conducting studies of adult child caregivers like Overall so they can offer better support. And there are plenty of candidates to study. Nearly 60 percent of cancer diagnoses and 70 percent of cancer deaths occur in the 65-and-older set. If a parent is widowed or divorced, or the spouse isn't physically or psychologically up to the task, the children often step in.

So children, whether they're in their 20s or 50s, immersed in a career and/or raising children, may suddenly have a new batch of responsibilities. The "sandwich generation," as they're famously called, must add visits to cancer doctors, support after surgery and chemotherapy treatments, and, in some cases, tasks like bathing a parent.

In It Together

A family meeting is the best way to embark on this new phase. If children live around the country, a phone conference is an option. The question: Who will do what? Or more specifically: Who has the time and inclination to do what? Should the parent attend? “It depends on the situation, but if the parent can participate, I think he or she should,” says Carol Levine, director of the Families and Health Care Project for the United Hospital Fund in New York.

“It may not be like dividing the pie when you’re 5 years old, when you can actually make it fair,” Levine warns. Typically, daughters take on more than sons: Estimates are that 70 percent of cancer caregivers are female, says Levine. Some siblings are able to pick up expenses not covered by insurance. Others may volunteer for chores. And some won’t do a thing, either because they live too far away or because they aren’t willing.

Sheryl Taylor, 45, of Richmond, Virginia, says her two sisters “clocked out” during the difficult final months of caring for their mother, who had pancreatic cancer. “They both didn’t think they could handle it,” says Taylor, who bathed her mother, gave her shots, and, toward the end, put morphine under her tongue with a dropper when the pain was too much to bear. A counseling session following their mother’s death allowed Taylor’s sisters to express regrets about not being there.

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If a sibling is unwilling to help, that doesn’t mean other members of the family should shun him or her. “Say, ‘This is what I need you to do,’ ” says Ruth McCorkle, a professor at the Yale School of Nursing and an expert on caregiving for cancer patients. “You can’t expect a person to change but could expect [him or her] to do a few things to help during that time.” If the siblings are willing, a session with a social worker or psychologist might help clear the air.

Quarterly or monthly follow-up meetings allow for revisions in the caregiving plan. So will meetings before a new stage of treatment. If outside help is needed, be it a home health aide or hospice care, the children must be honest with the parent.

Role Reversal

The time frame for caregiving is critical. Are the children making sacrifices for a short, intense period before cancer takes its toll? Or is the goal to get the parent through months of treatment with hope for a good outcome? Another possibility: The parent may live with cancer as a chronic disease for years to come. Both children and parent will face many decisions.

That’s what Colette Winston, and her sister, Gigi, found out during what Colette calls her mother’s “grand tour of cancer.” After three cancer misdiagnoses for Tina Winston, doctors determined in June 2006 that she, in fact, had a rare form of non-Hodgkin’s lymphoma. Since Tina’s husband has Parkinson’s disease,

Colette and Gigi became their mother's advocate, accompanying her to doctors' appointments, sending out slides to experts, and assembling a notebook to document her illness. Tina now takes Rituxan (rituximab) to keep her lymphoma in check.

Despite their caregiving responsibilities, the kids aren't the boss of the parent. "My mother is a very meek, mild person. She's not demanding at all," says Tracy Cook-Brewton, 37, of Gastonia, North Carolina. But when her mom was undergoing chemotherapy for breast cancer and lost her appetite, she resented her daughter urging her to eat or drink.

"It was difficult for me, and I imagine it was difficult for her also," says Cook-Brewton. "I think the patient is fighting for her life, for control." Cook-Brewton learned to back off, but she also advocated for her mother at doctors' appointments. "My mother is from a generation that didn't necessarily question their doctors."

As for lessons learned, "You've got to allow your parent to maintain their independence and guide you as they have done all along in your life," says Overall.

Winston agrees: "The bottom line is that Mom makes the decision." She'd take notes at the doctor's office, type them up, and then fax them to her mother for review.

But even if the parent is in the driver's seat, he or she may want to cede some authority to the child. "A gift a parent can give an adult child is to allow them to step into a position of greater authority," says psychologist Barry Jacobs, author of *The Emotional Survival Guide for Caregivers*.

Some parents try to maintain control by keeping their condition a secret or minimizing it. They may also be trying to protect their kids. Any patient has the right to privacy, but when it comes to rebuffing help, caregiving experts say parents should allow their children to express their love. Jacobs recommends just showing up—for dinner, for a doctor's visit. "Don't wait for an invitation, even if means erring on the side of intruding. A lot of parents don't want to ask for help, but if it's being provided, they will accept it."

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—Mary Overall

How to Deal

In April 2006, Lloyd Jones quit his job and moved in with his mother, whose ovarian cancer had recurred after several years. He's her medical aide, chef, and housekeeper. He's run through his savings (and is grateful for unemployment insurance). But he figures it's the least he can do. His dad left when he was 2, and Helen Jones raised him and two daughters and did a "wonderful job."

Ongoing chemotherapy has helped his mom, and in September 2007, she was “doing pretty good,” says Jones, a 39-year-old New Yorker. What Jones calls “me time” is a balm. Sources of strength vary: religion, exercise, meditation, keeping a journal, chatting with friends.

Support groups can lessen the caregiver’s sense of isolation. But many caregivers say they just can’t make the time. On the web, they can get some of the same benefits by reading (and posting) on message boards of various cancer sites. “As you get rid of those feelings you’re harboring, you sometimes gain the answers you need just by hearing yourself talk,” says Overall. Dumping out old emotions, she adds, helps her make room for the next round of challenges and concerns.

Cutting back on caregiving hours is another coping strategy, says Karen Fasciano, a psychologist who works with families facing cancer at the Dana-Farber Cancer Institute in Boston. Spending a little less time with a parent by pursuing outside interests might enhance the time spent together. “The child needs to have things to look forward to,” she says, “and the parent needs to see that the child’s life will go on.”

But a deepened intimacy can evolve, especially if the adult children have been able to carve out time for enjoyable activities and meaningful chats with the parent. And even a parent who is ill with cancer can be an inspiration, showing a child how to face adversity with grace, humor, and courage.