

Focus

Friends In Deed

A Special 'Family'

By Barbara Mathias
Special to The Washington Post

For just a moment, imagine the worst: Your doctor says you are seriously ill and there will be an unknown stretch of time when you'll be bedridden and undergoing painful treatment. After the initial shock, panic sets in. Who is going to care for you? Who is going to help you and your family manage the daily routine of living and the special needs of your illness?

That's what happened in 1988 to Susan Farrow, then 42, when she was divorced, raising two teenage girls, and heading the promotion department of Lever Brothers in New York. Her rare form of cancer, which had started in a salivary gland 41/2 years earlier, was kicking in again—this time with a tumor on her spine. Farrow was afraid that if the tumor paralyzed her, she no longer could be as independent as she had been. The petite redhead, known for her love of life and sense of humor, had deliberately chosen denial as her coping mechanism. Few

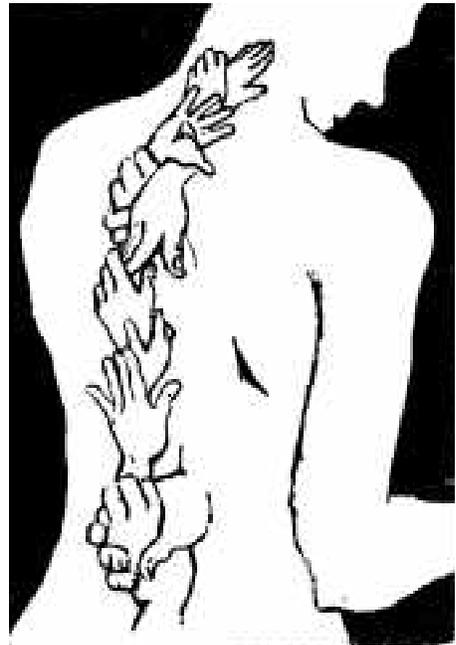
people even know she was sick and that's the way she wanted it.

Now it was time to ask for help, something she didn't think she could do for fear of burdening her friends or being rejected. Fortunately, Farrow had a psychotherapist, Sukie Miller, who encouraged her to create an organized plan of action for her care. Following Miller's orders, Farrow called 18 friends—no simple task because she had to admit to her illness—and invited them to a meeting at Miller's office to discuss how they could best help her. Twelve of them came.

"That telephone call changed my life," says Cappy Capossela, an advertising copywriter who had enjoyed Farrow's company only four times a year, when they celebrated mutual friends' birthdays. "I was leading a charmed by naïve life," she says. "I had never lost anyone but a grandmother. I never had a pet, never had children, never had a lot of sickness around me." Little wonder she was more than apprehensive when she entered Miller's office, not sure how she could possibly help out.

Sheila Warnock had a totally different reaction to seeing so many women answer Farrow's call. "I was a burned-out caregiver," she explains, simply. As Farrow's closest friend and only confidante, she had been at Farrow's side all through her earlier treatments and brief hospital stays. At the same time, Warnock had been caring for her ailing mother, whom she had just put in a nursing home.

Fatigued and wracked with



guilt, Warnock says she was seeing less of her friends and was losing business in her work as a freelance art director. "I couldn't sleep and I was always on the brink of tears," she recalls.

That night in Miller's office when Farrow broke down in tears as she began to talk to her group of friends, Warnock felt both compassion and "total relief" that the secret was finally out—and that the care of her friend could be shared.

Under Miller's guidance, the women pooled their resources and came up with specific tasks and assignments that they recorded on paper. By the end of the evening, they gamely dubbed themselves "The Funny Family" and pledged to help Farrow's real family enjoy quality time with her.

For 31/2 years the Funny Family grocery shopped, cooked and cleaned as a team. They accompanied Farrow to doctor and radiation appointments where they took notes

and asked pertinent questions when she was too ill or confused to ask; they carried the X-rays from doctor to doctor, kept track of all the medications and filled out hundreds of insurance forms.

There also were special challenges: When Farrow's daughter became engaged, they organized her wedding. And when Farrow wanted to try a six-month alternative treatment at a clinic in the Bahamas, the Funny Family managed it, fully aware that this wasn't a vacation. Combined with Farrow's real family, they divided the care among those who could leave their jobs, often switching off in a Caribbean airport with just a hug and an exchange of medical papers.

As Farrow became progressively worse, she relied on the group to boost her morale. They held her when she cried, and laughed with her on the days when her wit would suddenly break through. They put on her makeup when she wanted it, gave her a pedicure and gently washed her hair. They wrote letters for her, made phone calls, wrote out her checks and arranged for in-home health care and finally brought her to a hospice.

On Sept. 11, 1991, Susan Farrow died at age 46. To this day, her Funny Family is loyal to her memory and astonished at the power of their group. They are convinced that no one person—or even two or three—should be totally responsible for a sick person's care. They also are proud and grateful for each member's contribution to the group. In all that time only one person had dropped out, and two more had joined.

Six months after Farrow's death, another cancer patient, "Francine," contacted them to ask how she could form a Funny Family of her own. This time without any therapist in the room, Farrow's Funny

Family met with Francine's friends and walked them through the procedure. That night they taught them what they had learned: You can get something of this experience for yourself—it doesn't all have to be done for the sick person.

"Eventually, we got on a roll of doing these groups for others," says Capossela, adding that men also have sought their advice and formed such groups. "We hoped that people could replicate what we did. Our goal was to make it clear and simple and easy."

Capossela and Warnock, both in their mid-forties, have done just that by writing a step-by-step book "Share the Care: How to Organize a Group to Care for Someone Who Is Seriously Ill," (Fireside, \$13). This non-nonsense guide recognizes that the sick can be complainers and the caretakers can be control freaks. The authors give fair warning that members in the group may gossip, give unwanted medical advice, and compare what everyone else is doing—"She shouldn't be making her dinners, her eating habits are atrocious!" Then there's the inevitable problem of well-meaning caretakers overloading the patient with the logistics and details of the care, or even the problems that the group is having. They attribute such ill-suited communication to the fact that the caretakers typically don't know each other as well as they know the patient. They advise the group members to routinely meet for coffee and talk directly to each other, and restrain from asking judgments about each other.

In the Funny Family system everybody gets to be the boss, but never for too long. There's a constant rotation of coordinators, captains and co-captains who manage the group on a weekly basis. As for the size

of the caretaker group, it works with as few as eight people; ideally, there should be at least 10. If necessary, the group can include some "real family" members, but not too many or it will defeat the purpose of relieving the family. There also should be "free-floaters," that is, people who can't make a weekly commitment but are willing to be called on for emergencies.

The authors firmly believe that "If you try to do everything, the group won't work. If you don't trust each other to do the work, the person who is ill won't trust anyone." They give the familiar example of the person who doesn't trust the telephone chain method, so she makes all the phone calls herself. Or the person who signs up for one evening and then shows up for several evenings, just in case the others who are scheduled don't keep their commitment.

In the book, the authors have provided blank forms that can be photocopied and distributed. There are forms for telephone trees, as well as lists that record the strengths and weaknesses of group members ("I can't stand seeing needles or shots." "I love to care for pets."). There are more forms for keeping track of medications, insurance and medical documents, along with telephone and address forms for doctors, nurses, household help, family members and free-floaters. They also provide a home-safety chart and a resource list for making the sick room user-friendly.

Capossela points out that none of this planning can begin to take place until the sick person accepts that she needs a group to care for her. In some cases, it may have to be a family member or close friend, but it always has to be with the sick person's permission.

Once that is given, the mira-

cle of friendship somehow takes hold. "There are so many people who want the help," says Warnock, "but they don't know how to take the first step—and that's because they don't know what the first step is."

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Update Friends in Deed, II

By Barbara Mathias
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Lynn Mazur wouldn't give up on helping her friend, 34-year-old, Karen Hills, who was dying of lymphoma after courageously fighting it for 10 years. On Jan. 2, Mazur read an article ("Friends in Deed") on the Style Plus page about a "Funny Family" of friends who nursed a woman through her cancer so that her real family could be freed of the responsibility of daily care. The very next day Mazur bought and read the book described in the article: "Share the Care: How to Organize a Group to Care for Someone Who Is Seriously Ill," by Cappy Capossela and Sheila Warnock (Fireside, \$13). That evening, she called her friend Karen and Karen's husband, Cornell, saying, "I want to come over and talk to you. I have an idea."

As they sat in the Hills' living room, Mazur explained how she would be the "meeting leader" and would organize a crew of friends to help with the logistical care of Karen and their 7-year-old child, Alicia. With this highly organized, voluntary method, no one person is burdened with the care, she reassured him or her. "Her husband, Cornell, just sat there saying, 'Thank you, thank you,'" recalls Mazur. In the past 20 months, their life

had become a complex existence. Everybody was exhausted. They didn't know who to call for help."

With the Hills' permission, Mazur quickly rounded up 29 friends, men and women, many of them from a Jazzercise program in Fairfax where Karen and Cornell were students at one time. Many came to that first meeting because they knew Cornell and not Karen; all of them wanted to help.

Karen was then chair-ridden and her muscles were failing. Because of her terminal diagnosis with little time to live, she had no insurance to pay for physical therapy. Within days, the dancers were taking turns exercising and massaging her limbs. Other members of the Funny Family helped with the daily and loving care of Alicia, as well as the logistics of running a household.

Because of the high cost of the care in the previous year, and the loss of insurance, the Jazzercise class told Karen and Cornell that they would conduct a fundraiser on April 12; it would be an evening of special jazz classes open to the public, a silent auction and potluck supper. It was an event Karen was looking forward to, but she wasn't sure if she would make it.

Karen Hills died on March 25. On that day, the last thing her friend Lynn Mazur told her was, "The brightest moment of the comet will be tonight." For this, Mazur is grateful: "She could hear me."