

# Creating a Caregiving Family

Sheila Warnock's father was a teacher and her mother a nurse, but she had "no desire to be either." Her creativity led her into a career as an advertising and creative director where she learned to work with different teams of people. Little did she know her familiarity with these three professions would prove to be grist for the mill for her current role as a pioneer in reinventing caregiving for the 21st Century.

The caregivers Warnock is targeting now are those caring for someone with Alzheimer's or other memory loss diseases. She's preparing a third edition of her highly respected book, *Share the Care: How to Organize a Group to Care for Someone Who Is Seriously Ill*, which will be released next year. The second edition was judged by *The Library Journal* to be "one of the best consumer healthcare books of 2004."

"I always knew Alzheimer's was one of the more difficult challenges for caregivers," she said. "I felt the need for a Share the Care group to be able to function in that environment."

The caregiving model Warnock created with her friend Cappy Capossela seems so obvious it's a wonder no one thought of it before. Her evidence-informed system of bringing together a large caregiving team is an intentional practice of what people have been doing for years in less charted, smaller ways. This leads to a large-scale caregiving family pooling their resources with no one burning out or being isolated.

Her journey began when her close friend, Susan Farrow, needed assistance as she lived with advancing cancer. Because Farrow had no family nearby, her therapist, Sukie Miller, suggested she schedule a meeting and invite as many friends, neighbors, colleagues and others that Farrow could name. Miller presided, helping Farrow to identify her needs and the members of the group how they could meet those needs — together. Over the three and a half years before Farrow's death, they developed a system that engaged the caregivers without any one person feeling burned out. That system is outlined step-by-step in *Share the Care*, which includes a workbook filled with well-tested materials.



"Bob's Brigade" caregiving family



"Morning Glories"



The first "share the care" caregiving group: Susan Farrow's "Funny Family"



## Share The Care SEVEN PRINCIPLES<sup>®</sup> FOR TEAM BUILDING

- 1 Sharing responsibility is key to not burning out.
- 2 Know your limits and stick to them.
- 3 It won't work unless everyone gains something personally.
- 4 There's no one right way to do it.
- 5 Anyone who wants to help should be encouraged.
- 6 Trust the group; support each other.
- 7 Keep your own life in good working order.

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## CREATING A CAREGIVING FAMILY *cont'd from p. 17*

“The first meeting is the heart of everything,” Warnock says. Participants fill out sheets rating their strengths and availability. An extensive list of tasks that are likely to arise are assigned accordingly. Tips are given for how to approach someone who might be reluctant to accept care and how to anticipate and avoid the most common caregiver problems.

“She developed it by doing it,” says Gregory Johnson, president and CEO of Greg Johnson Partnerships, Int’l, Inc. and chief advisor for Family Caregiving, Office of the CEO, EmblemHealth. “Her mission came from her journey. She found something missing and created it. That is the story of people devoted to caregiving.”

Warnock sees a need to add a section on forming a caregiving family for someone living with Alzheimer’s because the way this disease manifests “is all over the map,” turning talkative people quiet or causing gentle people to fight or run away. “It’s much more intricate than how cancer manifests.”

Share the Care’s system will allow people who live by themselves to remain independent longer. Doctors in the field agree that many people in the early stages of Alzheimer’s can live alone if they have routine and ongoing care.

Someone who lives alone has a greater need for a support group, Warnock says, and the members must be “very, very connected.” Church volunteers or others helping out don’t provide this kind of intensity of care.

“A Share the Care group knows the person,” Warnock says. “That’s what makes this group unique. We don’t just tell a volunteer what to do. We teach teamwork.”

Many of the relationships continue long past when the care has ended.

“Everything starts with a group. You can’t change the world by yourself. Nobody has all the answers. If each person brings special abilities, together that will make it bloom.”



Members of the “Care Crew”

Photos courtesy of Sheila Warnock