

TAKE CARE!TM

Self-Care
for the Family
Caregiver

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*I*t's not easy to ask for help. For family caregivers, this is especially true, as the very definition of your role is one of devoting yourself to caring for someone else. But what happens when you, the family caregiver, recognize the need for outside assistance and are unable to find that assistance through the "usual" channels? As some family caregivers have learned, it sometimes becomes necessary to think of creative ways to let those around you know you need help, or to help one another. With the hope that we will inspire others to find their own unique solutions, TAKE CARE! highlights the stories of three individual family caregivers and one group of citizens who did just that. Some names of family caregivers and their loved ones have been changed to protect the privacy of those involved.

The Power of the Press

For five weeks in the fall of 2004, Pam Dimings didn't leave her house. As the sole caregiver for her husband, Randy, whose multiple sclerosis had left him unable to talk,

walk, or even move his limbs, Pam was, literally, a captive in her own home. While a registered nurse visited twice per week to change Randy's feeding tube or catheter, and a personal care attendant would help empty his colostomy and urine bags, it was necessary for Pam to remain at home during these visits. "I felt as if I was trapped and I couldn't get out," she says. "All I needed was a few hours to get out."

Being stuck at home was nothing new for Pam. Four years earlier, she had devoted herself to her husband's every need. She was his caregiver 24 hours a day, seven days per week. For a little more than two years of that time, Pam had received 120 hours annually of unskilled respite care through Medicaid. While not much, the breaks were enough to keep her going. About a year ago a new case worker assigned to the family promised to get more respite care for Pam. Instead, the unthinkable happened. When the case worker contacted Medicaid to get more respite hours approved, she discovered that Pam shouldn't have been receiving any respite care at all. Because

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Family Caregivers Reach Out And Communities Come Together In Unusual Ways

Randy was unable to direct his own care, Medicaid had been mistaken in allowing unskilled help in Pam's home. The case worker broke the news to Pam that she would no longer be offered the very assistance on which she had come to rely. Thus began Pam's five weeks of home confinement.

Forced to rely on her friends to bring her groceries and without the

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money to pay for private respite services, Pam felt increasingly desperate and alone. She decided to reach out to anyone who might be willing to help. One of Randy's nurses heard a local newspaper healthcare reporter on the radio and gave his name to Pam. She contacted the paper and left him a message. "I asked him to do an article on family caregivers and our desperate need for help," she says. "Our government has let us down healthcare wise. This is a situation that needs to be addressed." Pam urged the reporter to do a story on the plight of all of America's family caregivers. After a few phone conversations, he agreed.

Within days of the story appearing in the local paper, Pam began receiving phone calls from people who wanted to help. Soon, Pam had a volunteer to watch Randy one day per week for four to five hours so that she could run errands. Another woman offered to watch Randy on Sundays so that Pam could attend church services, something she deeply missed being able to do. These women continued to help Pam and Randy over the next few months, until his death in January of this year.

Pam feels heartened by the fact that in her own small way she has helped raise awareness about the needs of family caregivers. "One of the women who helped me out told me that she now realizes that there are other people who could use her help," she says, proud of the fact that her story may now make a difference for someone else in need.

Finding Help Through the Click of a Mouse

Although suffering the effects of Parkinson's disease, "Ian" continued to commute to his job in downtown Atlanta, Georgia, three days per

week. He telecommuted the other two days. In recognition of the severity of his symptoms, however, Ian recently decided to hang up his car keys, an agonizing decision that resulted in a huge loss of his independence. In an effort to keep from becoming completely isolated by his condition, he decided to attempt to find transportation downtown three days per week. He turned to his wife, "Janet," also his family caregiver, who was much more comfortable asking others for help.

Janet decided to approach a trusted neighbor, "Paul," who worked across the street from Ian. "Being much more of an extrovert than Ian, I had no problem approaching our neighbor to find out if he'd be willing to drive Ian to work one day a week in our accessible minivan," says Janet. The neighbor agreed to give it a try.

With one positive experience under her belt, Janet decided to take her request one step further. She posted a notice via her temple's e-mail list. While waiting for a response, Ian tried using a handicap accessible taxi service to take him to work, but its expense, plus the uncertainty of whether the car would actually show up on time, made it a prohibitive long-term solution. Janet, meanwhile, had not received a response from her temple's contact list, so she decided to widen her search. She posted a notice on her neighborhood association's Listserve, still hoping to reach someone who worked near Ian and would be willing to help out a neighbor. "Lo and behold but who should answer but a neighbor we had just met at a mutual friend's home," says Janet. The neighbor, "David," understood what Ian and Janet were going through because he, too, was living with someone who suffered from Parkinson's. In fact, David had just moved to the neighborhood because he and his partner needed a home that would better accommodate his partner's

increasing disability. David owned a store near where Ian worked and offered to provide transportation for Ian one day per week. In the meantime, the arrangement with Paul was going so well that he was now transporting Ian to work two days per week. The two were becoming fast friends in the bargain.

Several weeks into his new arrangements, Ian has been able to maintain his work schedule and has benefited from a reduction in the fatigue that he had experienced when driving himself. Janet reflects on the turn of events. "It all happened because we weren't afraid to put ourselves out there; we weren't afraid to say, 'We need help,'" she says. "Serendipity played a role, of course, but that is part of the point."

Responding to a Literal Call For Help

"Gordon's" wife was diagnosed with MS in the summer of 2004. In his attempt to learn as much as he could about her diagnosis and her prognosis, Gordon decided to tune in to a national MS caregiver teleconference that was scheduled for mid-November. The night of the teleconference, Gordon was one of the lucky few chosen to have his question broadcast across several states. While waiting on the phone for his turn, Gordon listened to the caller ahead of him describe her difficulties caring for her husband and how desperately she could use a handicap ramp at her home. As the call continued, Gordon listened in amazement as he discovered that the woman caller not only lived in his state, but in his community. Anxious to help a fellow family caregiver in need, he asked the MS staff handling the teleconference to hook him up with the previous caller. They did so and Gordon soon went to work. As a manager in an architectural and engineering design company, he sent some members of his staff to evaluate the woman's

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home to see what needed to be done. He even offered to pay for part of the construction costs himself.

Gordon is currently in the process of trying to find funding to cover the major costs of the ramp, and to work out the various zoning and construction issues that must be addressed for the project to move forward. Asked what other family caregivers can learn from his experience, Gordon doesn't hesitate to explain how much of a role fate can play when he says, "Sometimes it's all in God's plan. You just have to be aware and listen."

Coming Together to Help Each Other

While some family caregivers have discovered innovative ways to reach out to their community to find the help they need, others are joining together cooperatively in an effort to help each other and the entire community. The SeniorCare Cooperative of Swarthmore, Pennsylvania, is one example.

Launched in the spring of 2004 by a small group of concerned seniors and healthcare professionals in response to requests from area seniors, the Cooperative is a non-profit organization designed to bring home- and community-based services to individuals who have chosen to remain in their homes. "The idea is to keep members of our school district in their homes for as long as possible," says founding member Judie Neale. The Cooperative provides assistance with such services as home care, respite care, transportation, meals, and home maintenance services. While it is promoted to seniors, the program is intergenerational, providing services to anyone in the community in need, regardless of the age of the care recipient.

Memberships in the Cooperative are available to everyone in the

Swarthmore school district. After an initial fee of \$50 to join, there is a monthly maintenance fee of \$25 per household. As part of that investment, members receive 24-hour access to one of two personal care managers. Judie Neale serves as one of these managers, using her expertise to locate any service the family needs, to coordinate benefits, and to conduct daily checks on the family to ensure that everything is going smoothly. She will even keep out-of-town family members up-to-date on the well-being of the care recipient and the family caregiver.

The Cooperative has even reached out to other local groups to broaden its ability to help its members. A number of area churches provide volunteers as needed to assist SeniorCare Cooperative members. In addition, a local youth support group provides a reliable and steady stream of young volunteers who will do everything from running simple errands to lawn mowing and snow removal for those in need.

The biggest challenge for Neale and the Cooperative is convincing area residents that it's important to join *before* a crisis occurs. With nearly 2,000 senior households in Swarthmore, relaying that message has been a priority. "It's easy for folks to say, 'This is a great program but I don't need to join it yet,'" says Neale. "The hard part for us is getting people to acknowledge that it's important to become a member of the Cooperative *before* they experience a crisis. That way, I can get to know their history, what medicines they take, etc., and I will be in a better position to get them the help they need when the time comes." Mailers to areas homes, links on related Web sites, brochures in doctors' offices, and positive word of mouth have all contributed to a flurry of calls for Neale, who hopes that the Cooperative will serve as a model for other communities around the country.

Another program that may serve as a model is Beacon Hill Village in

Boston, Massachusetts. Billed as a "virtual retirement community" for area residents who are age 50 and older, Beacon Hill Village has partnered with a number of service providers, including doctors and hospitals, to help its members receive cost-effective services such as home maintenance, medical care, home healthcare, transportation, and meals and grocery shopping. Beacon Hill residents and those in adjacent neighborhoods can join Beacon Hill Village for \$550 per year for an individual and \$750 per year for a household. For low- and moderate-income individuals, Beacon Hill Village offers a Membership Plus program, with significant discounts on membership fees and credits that can be used toward any of its programs or services.

While their methods may be slightly different, the concept behind Beacon Hill Village and SeniorCare Cooperative is the same: Neighbors helping neighbors remain in their homes by providing the services they need in a safe, comfortable, and familiar setting.

Being Open to Something Different

Whether it's sharing a personal story with a local newspaper, posting a message on a community Listserve, taking part in a national teleconference, or being receptive to a different kind of service organization, the answer for some family caregivers may be found when they allow themselves to open up, and come together, in ways they may never have considered before. The key is to remain open to new ideas, to new ways of looking at a problem and its possible solutions. When the standard avenues of assistance lead to dead ends, being able to "think outside the box" may make the difference between burning out and finding the help you need. ■

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