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# Caregiver Access to Resources — Helping Caregivers Self-Identify

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*The reluctance of spouses and family members to identify themselves as caregivers is an obstacle to providing services to them. The East Central Kansas Area Agency on Aging has an outreach program that is overcoming this barrier. When members of the helping professions refer caregivers to the agency, invitations to a caregiver luncheon follow. For many it is the first time they have spoken out about their experience to someone they didn't already know. The programs and resources of the Agency then becomes their ace in the hole.*

Obstacles to providing services for caregivers are many; however, the biggest obstacle may well be the reluctance of family members and spouses to identify themselves as caregivers. This reluctance is especially true of couples.

My experience at the East Central Kansas Area Agency on Aging is that older adults, especially if they have been married a long time, expect the aging process to lead to an increased dependence by one on the other at some time. They believe that as one partner is less able to help, the other will do more; and between them, they can remain independent in their homes. Their goal, however, becomes harder to reach as the frail spouse becomes frailer and the caregiver continues to age.

These couples often tell us that they came of age in a time when divorce was not an easy option to exercise if things got tough. They married "in sickness and in health" and to them, the fact that they are now "in sickness" merely seals their commitment. In their minds, giving care is not doing anything special or heroic. It is simply honoring their marriage vows. Consequently they

do not always acknowledge that they need help, or identify themselves as caregivers for whom help is available.

Nevertheless, the responsibilities and tasks related to caregiving are not necessarily what most people envision they will be doing late in life. A man or a woman does not marry to become a nurse, physical therapist, pharmacist, social worker, nutritionist, or other kind of professional caregiver. Yet they quietly assume these responsibilities as they arise. And too often, they must assume these responsibilities with little or no training. As a result, linking caregivers to resources can be a difficult and time consuming task. It begins with the effort to identify who the caregivers are in each community.

## **A Brown Bag Beginning**

To help people identify themselves as caregivers, we scheduled a series of brown bag lunches in different communities in each of our six counties. We did not, however, invite spouses or family members; instead, we invited other professionals. We included personnel from churches, pharmacies,

doctors' offices, health departments, home health agencies, and providers of durable medical equipment. We also invited hospital social workers, extension agents, nursing home and community mental healthcare workers, and other professionals who work with older adults.

We invited these professionals to the brown bag lunch, hoping they would find it easier to schedule their lunch breaks than to add another meeting to their busy schedules. We introduced them to our agency and caregiver programs, and asked them to help us identify community caregivers. We provided them with release forms for the caregiver program, and asked them to give a copy of the release to any caregiver they identified.

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We then used this information to compile a mailing list of caregivers willing to receive information about our programs, and used this list to inform caregivers about caregiver meetings and support groups. The list was not inclusive, but it gave us a starting point. Once we had met these caregivers in support groups or face-to-face, we also asked them to make peer referrals, but only if the caregiver had given his or her permission to be referred.

To further publicize this issue, we commissioned a series of four articles (which I wrote as the Community Services Coordinator), and submitted these articles to the newspapers in our six-county area. The articles were printed one per week during the month of September. The purpose of the articles was to help caregivers identify themselves as caregivers and avail themselves of important resources.

The identification of caregivers remains an ongoing quest, but the brown bag lunches and newspaper articles gave us a measure of success. Since that time, we have also asked the women's groups at churches in our area to help us educate the public about caregiver programs. Speaking to these groups has brought in additional caregiver referrals and improved our outreach efforts. After all, our programs, resources, and services for caregivers are of no benefit to them if they cannot access the information.

### **Caregiver Luncheons**

Once we had engaged so many professionals in helping us identify caregivers, we used their information to invite caregivers into our programs, beginning with the caregiver luncheon. We have sponsored thirty-six caregiver luncheons in our six counties during the last two years. The response by caregivers is consistent, but not in the way we thought it would be. We initially believed the luncheons would generate more demand for our services, and it did, but only to an extent. We thought they would be an opportunity for caregivers to learn about services and resources that they didn't know about. We were surprised by what we learned.

We hold these luncheons in hospital meeting rooms, nursing facilities, and assisted living facilities. These locations are chosen for two reasons. The first is the availability of meals. We don't have to cater the meals or worry about privacy as we might have had to in more public settings. The second reason is that each of the facilities we contract with for this service agrees to provide respite on site if needed, and at a prearranged fee that we have agreed to pay. So far, we have used respite care only once, as most caregivers have agreed that having their loved one in the other room would limit their ability to relax and focus on why they were there.

The format for the luncheons is simple. We begin with introductions by the participants, including a brief description of their caregiver responsibilities.

In some instances, this may be the first time they have spoken out loud about what they are dealing with to someone they didn't already know. It can be a very emotional time, and both men and women as caregivers struggle to articulate their experience.

Once we have completed the introductions and shared our stories, we are about thirty minutes into the luncheon. Amazingly, this short time is enough for walls to come down, and for the caregivers to become comfortable with one another. As we eat, they visit and talk and most of them bond very quickly. We try to get back into discussion after about twenty minutes, usually before they have finished eating, but they listen as they eat.

We provide information about our agency and the resources, services, or other benefits that are available to caregivers. We consider this time to be

the educational part of the meeting. Our agency has the blessing of a caregiver van as a resource, so we tell them about it. It contains free, printed materials, a lending library, a sampler of incontinent supplies and durable medical equipment.

### **Reluctance to Accept Services**

Once we have discussed available resources, we talk about specific questions our guests may have about their particular circumstances. We talk about stress, legal issues, accepting help, and how they are doing, in general. The two hours pass quickly, and each luncheon is slightly different because the participants and their needs are different. The one constant, however, is the reluctance of caregivers to accept anything from us.

They let us provide a meal and listen to what we have to tell them, but they do not follow through

### **How to Outfit a Resource Van**

1. Stock the van with free printed materials and invite caregivers to help themselves.
2. Create a lending library of books and videos on caregiving. Allow caregivers to read the books and view videos in their homes, and when finished call the agency to schedule a pick up. Don't risk losing your materials in the mail. Include in your library:
  - Materials that are disease, or medical-condition specific, such as caring for persons with Alzheimer's or Parkinson's.
  - Books containing general information related to caregiving and how to do it (physically).
  - Resources that are spiritual in nature, (i.e., that focus on one's emotional and mental states).
3. Add a sampler of incontinent supplies. You may not be able to provide incontinence supplies on an ongoing basis, but you can provide samples.
  - If incontinence is a new concern, the caregiver may not know which product is best.
  - By sampling a few products, caregivers save money and avoid frustration.
4. Put some durable medical equipment on the van, for example, a transfer bench for the shower, a toilet riser, a bedside commode, and grab bars. Allow caregivers to try the equipment.
  - If it facilitates safer or easier activities, let them buy it (and use the money to restock the van).
  - If they elect not to keep it, they have not lost any money on the item.

with a request for services. They may do something related to better planning; for example, they may talk with an attorney, or bring a family member in on their financial circumstances. But they do not accept services in general, or respite care in particular.

This reluctance to accept services is not the outcome we anticipated when we began the caregiver luncheons. We expected to see an increased use of our caregiver resources, but instead caregivers are apparently storing the information we give them as an “ace up the sleeve.” While they are not requesting the programs or services now, they like knowing where and what these resources are in case they decide to act. I am not saying that caregivers never use our programs, but those who do are the exception, not the rule.

As a result, we provide some in-facility and in-home respite. We loan out books and videos; we provide durable medical equipment; and we give away tree loads worth of printed materials.

We tell our luncheon guests that we are the pebble in the water, and they are our ripples, spreading the word throughout our communities. And, surprisingly enough, even when caregivers feel overwhelmed themselves, they are still willing to help one another.

We will continue to seek new and innovative ways to find and help caregivers. The largest barrier continues to be their unwillingness to identify as caregivers. We view this barrier as simply our biggest challenge for reaching caregivers who have never been reached before.