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Repository Citation

Rappaport, Judith B. (2002) "Elder-Caregiver: An Alarming Past, An Uncertain Future," *Marquette Elder's Advisor*: Vol. 4: Iss. 1, Article 5.

Available at: <http://scholarship.law.marquette.edu/elders/vol4/iss1/5>

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Elder-Caregivers: An Alarming Past, An Uncertain Future

Increased life expectancy is exacerbating the financial, physical, and emotional pressures on family members struggling to care for elderly parents. Elder law professionals have a unique opportunity to positively impact this situation by educating themselves and their staffs to the family caregiver's needs. This article identifies those needs and recommends expanded services to help meet them.

By Judith B. Rappaport

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"If you really want to help this world, what you . . . have to do is teach folks how to live in it."

—Joseph Campbell¹

It is unlikely that Mr. Campbell was referring specifically to elder-caregivers, but he easily could have been. You know the numbers:

- Family members provide over eighty percent of the care for elderly loved ones.²
- Family members inflict seventy-five percent of the abuse their loved ones suffer.³
- U.S. corporations report losses of up to \$29 billion annually in lost time due to caregiving duties handled from the workplace.⁴

It seems that although almost everyone has a stake in easing what has become a national burden, no one has figured out exactly how to do so. What happened in our society to bring elder-caregiving to a scope of this magnitude? The easy answer is: Society slept while science expanded our life expectancies.

The longer version is that financial and housing issues took so much of our time and budget that as long as family caregivers assumed the responsibility, their seemingly ancillary problems never made our "to do" lists. Decades ago, during a simpler medical era, that might have passed for an acceptable norm. Today, because of insurance constraints, the norm for many family caregivers includes medication and treatment procedures that until recently were forbidden to all but licensed healthcare professionals. Every medical breakthrough that expands life expectancy compounds the already significant financial, physical, and emotional pressures on families struggling to maintain a healthy and safe quality of life

for their parents and themselves. Our current system borders on a national program of caregiver neglect and abuse.

The potential for a breakdown in the familial and economic structure of our society is staggering. Elder law professionals have a unique opportunity to impact this seemingly endless negative circle by educating themselves and their staffs to the family caregiver's needs. This article identifies those needs and recommends expanded services to help meet them.

Today's Generic Family Caregiver

Because becoming a family caregiver is often a crisis-driven decision, adult children who accept the responsibility of family caregiver rarely look at their parents' needs in a realistic or practical light. They seldom consider the additional work-hours their new responsibilities will add to their lives. It is unrealistic to expect these teachers, artists, and accountants to recognize, without professional guidance, that the very nature of old age or illness ordained that their parents would need increasing assistance over time.

Walk through an office building and ask women over forty-five if they expect to be involved in eldercare. A double-digit percentage will respond in the affirmative.⁵ Follow up and ask if they have thought about training to become a caregiver or have planned for the responsibility with other family members and most of them will respond with a negative answer. Whether the reason for this lack of planning is denial, ignorance, or financial or time constraints, the result is usually the same: burnout.⁶

Burnout is so common among family caregivers that it is often accepted as "part of the job."⁷ In fact, it often goes unnoticed until the caregiver verges on exhausting all her physical and financial resources or turns to the healthcare system for treatment. At this stage, the caregiver has often lost her job, her spouse, and most of her quality of life. When the family loses the services of the current caregiver, it begins searching for a replacement. The scenario repeats until the supply of replacement caregivers evaporates.⁸ At that point, the family places mom in a nursing home.

The Long-Distance Family Caregiver

Long-distance caregivers are particularly vulnerable. Those who assume their roles in the midst of a crisis usually do so alone. Without a preplanned support

system and access to the correct resources, they have no way to evaluate critical information and make informed decisions. In the chaos of leaving home as quickly as possible to reach their parents, they may not have had the time to gather important data or telephone numbers. Their ability to reach the professionals who hold legal documents or control finances may be limited or nonexistent.

Without knowledge of state or insurance law, these caregivers are even more at risk than generic caregivers. It is easy to sit back and say, "What were they thinking? Why didn't they have a plan?" Plan? Hard as it may be to fathom, the reality is that many do not even have a telephone book from their parent's home area! For some, the concept of an ill or dying parent is too horrible to face. For others, denial is the easiest route—no need, no work to do. But most just do not know how or where to begin. Regardless of the reason, the result is the same.

Long-distance caregivers often lose the option to choose their advocates. They may feel forced to accept services from professionals who cannot meet their needs, from nursing homes that fall below standard, or from inappropriate home-care services. They may begin to feel impotent and become fearful and resentful instead of productive. At that point, without strong professional intervention and advocacy, the family has every chance of becoming another nameless statistic at the mercy of "the system."

Opportunities for Elder Law Professionals

In 1999, at the annual conference of the American Society on Aging, Dr. Mike Migliaccio, president of the respected national research firm Maturity Mark Services, shared the results of a survey demonstrating that caregivers wanted information and education.⁹

What they want is practical advice that will help them resolve the multifaceted, twenty-first century issues they face. Too often, what they receive are textbook solutions that apply only to fairy-tale versions of single-issue problems.

We do not have to accept this scenario as the inevitable. Elder law attorneys can help reduce the negative impact of caregiving by creating or joining with other professionals in aging-related fields to develop an expanded service line that includes education and referral services for adult children of aging parents. Here are some simple examples:

- **Don't refer. Coordinate.** Handing a stressed-out caregiver a list of telephone numbers to call for assistance may be, in his or her mind, not much different than copying a page from the telephone book. There is no doubt that it is often helpful, but why not provide full service for caregivers who require or request it? Train a staff member or hire a social worker to act as an initial service coordinator. You can simply say, "Jan will take you into the other office and assist you in finding the help you need."

For caregivers who decide to make their own calls, be sure your list includes contact names for every organization. Remind the caregiver to say, "Attorney Jones referred me to you." This will help establish an identity for the caregiver and may actually mean a difference in the level of service he or she receives.

- **Get feedback.** If you recommend another professional or a service without following up, you might inadvertently be contributing to the problem, or even escalating it. Let clients know how important they are by asking them to let you know if they are unhappy with your referral.

In reality, until you actually refer people to them, it is difficult to know how your colleagues actually perform or how they communicate with clients. Spotting problems should be easier. When you see a pattern of dissatisfied clients, drop the resource from your list.

- **Counsel or train caregivers.** Help acquaint both client and non-client caregivers with their options by offering workshops for clients or for prospects. You can hold these workshops in your office or in concert with community organizations at their offices. Not only will this help unclog the system, a steady program will help increase your market share. Work alone or join with a complementary service. Do not ask others to participate until you have heard them speak.

Strive for objective, independent professionals who are not afraid to share their experiences. The key is to provide practical, achievable solutions that caregivers can easily implement on their own. Stay away from

professionals who use workshops only for business development. They rarely offer enough information to solve problems and can actually exacerbate the caregiver's dilemma.

- **Create a caregiver-friendly environment.** Make your staff aware of how important it is to smile, make eye contact, and face clients while speaking. This is sometimes difficult for younger staff, who might feel unsure around stressed or grieving clients.

Train your staff to speak slowly and distinctly when leaving a callback telephone number. Instruct staff not to rush through their messages. They should always say, "Let me repeat that number," and, when doing so, speak slowly enough for the person to write it down.

Take the rock and roll or heavy metal music off your telephone. It is not about the type of music you like to hear. After all, how often does your office put you on hold? Your job is to bring a quiet, gentle order into a disordered world.

- **Build an information network in your office or on your Web site.** A primary need for elder-caregivers is information. A file of brochures for complementary services makes it easier for long-distance caregivers to amass information to take home. It also helps local caregivers who are overstretched for time.

Be selective. For example, most caregivers do not know that the Pharmaceutical Research and Manufacturers of America offers prescription drugs at no charge to patients with limited means. The drugs are obtained with the assistance of physicians and detailed information can be found over the Internet.¹⁰

Conclusion

We are the first generation of professionals in the history of the world to care for an elderly population. If the pundits are right, and we learn from history, we must assume people are taking notes in hopes of learning from us.

What will our legacy be? Will we, by omission, say that we were willing to turn away and wait until society caught up with science? Or will future professionals say that as pioneers in our professions, we understood our obligations to the generations that

followed, and developed powerful visionary skills and new perspectives?

Endnotes

1. Maria J. Oberhausen, *Conscious Planning With Older Adults*, 12 J. OF THE SOC'Y OF CERTIFIED SENIOR ADVISORS 21 (2001) (quoting Joseph Campbell).
2. *Id.*
3. Kristen Downey Grimsely, *Elderly Care Exacts Huge Corporate Price*, *Wash. Post*, June 13, 1997 at G3, citing, NAT'L ALLIANCE FOR CAREGIVING/AARP, *Family Caregiving in the U.S.: Findings From a National Survey* (1997), available at http://www.metlife.com/Business/Images/study_final.pdf (last visited February 14, 2002).
4. *Id.*
5. *See generally, id.* The survey completed by the National Alliance for Caregiving/AARP for MetLife Mature Marketing Group found that more than one-eighth of America's workers, or some 14.4 million Americans, are balancing elder care responsibilities and full-time or part-time employment. The survey also found that the average primary caretaker is a 46-year-old woman, but even workers in the 20 to 30 age group reported caretaking responsibilities because they were helping their parents care for elderly grandparents. Workers surveyed said their burdens were trailing into the workplace About 10% of all caregivers quit their jobs, about 11% take leaves of absence and about 59% miss some work by tardiness or taking long lunches to deal with care-related responsibilities. Most of the respondents said they spent at least one hour a week on the telephone handling calls related to such care.
6. *Id, see also*, Barbara Richardson, *Elder Care Strategies Part Three*, available at <http://www.newhomemaker.com/family/elders/burnout.html> (last visited February 14, 2002) (A 1998 National Family Caregiver Assn./Fortis report found that between 30% and 40% of caregivers were between the ages of 51-65, between 20% and 30% were over the age of 65. In addition, 70% of care recipients are more than 50 years of age and almost 50% of them are spouses); *Nat'l Family Caregivers Ass'n., Member Survey 1997: A Profile of Caregivers*, available at <http://www.nfcacares.org> (last visited February 14, 2002).
7. *Id.*
8. *Id.*
9. John N. Migliaccio, Address at the American Society on Aging (March 6, 1999).
10. Detailed information and a directory of the drugs offered can be found at <http://www.phrma.org> or at (202) 835-3400.