

Newsletter

National Center on Elder Abuse

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Special Theme Issue:

Caregiving and Elder Abuse Prevention

Contents of this special theme issue on caregiving and elder abuse prevention:

- Administration on Aging, NCEA spotlight caregiving issues
 - Caregiver handbook
 - Other AoA caregiver resources
 - Caregiving research review
- National Family Caregiver Support Program funded
- Book reviews
 - *Coping with your difficult older parent: A guide for stressed-out children*
 - *Another country: Navigating the emotional terrain of our elders*
 - *Ending elder abuse: A family guide*

Community Coalitions Section

- Spotlight: Sonoma County (CA) Elder Abuse Prevention Council
- Tips: Committees to the rescue
- Note for newsletter editors
- Reaching the National Center on Elder Abuse
- Elder abuse listserv available

The National Center on Elder Abuse (NCEA) is participating in this effort by working to create new and highlight existing resources designed to help caregivers of vulnerable elders and other adults prevent abuse, neglect, and exploitation. This special edition of the *NCEA Newsletter* will launch the NCEA caregiver initiative, which also includes a separate section on the NCEA website (<http://www.elderabusecenter.org/family/index.html>) and preparation of a comprehensive caregiver abuse-

prevention packet to be released later this year.

Many of AoA's new caregiver resources are available on the Internet.

Caregiver Handbook

One of the more innovative of these resources is "Because We Care: A Guide for People Who Care," at www.aoa.gov/wecare/. This handbook can be printed out

Administration on Aging, NCEA Spotlight Caregiving Issues

As part of the Older Americans Act's new National Family Caregiver Support Program authorized and appropriated late in 2000 (see article later in this newsletter), the Administration on Aging (AoA) has launched a multi-pronged effort to coordinate and expand services and supports available to family caregivers.

for reference away from the computer, but reaches its full potential on-line because of the hundreds of links imbedded within the text. It begins with five surprisingly detailed and blunt stories of AoA staff's personal experiences with elder caregiving. With this firm grounding in reality, the manual then moves into 12 specific areas:

- Where can we turn for help?
- What services can help us?
- How can I care for both of us?
- How can I improve our quality of life?
- What housing options are available?
- When your care receiver lives with you
- Living day to day
- How can we afford long-term care?
- How do I hire a home care employee?
- Living with Alzheimer's Disease
- How can I make my special needs child's future secure?
- Who will care if I am not there?

In addition to discussions of the basics caregivers need to know about each topic, every chapter includes additional resources and reading lists which may include links to federal government, national organization, and commercial websites. Certain words are highlighted in the text, and these link to various websites that can provide more detailed information, some of which caregivers might otherwise never find. For instance, the #1 "Caregiver Do" – getting sufficient sleep – links to a Food and Drug Administration article on "How to Get a Good Night's Sleep." A sentence on how some care receivers might need special oral hygiene care links to the National Oral Health Information Clearinghouse page on resources for special care patients.

Elder abuse is directly mentioned only in the chapter on hiring home care employees, where there are links to NCEA and its chart of state reporting numbers. In addition,

other sections' links to legal information would be helpful to caregivers trying to prevent abuse and exploitation.

Overall, "Because We Care" is an excellent addition to the caregiver literature, and is well worth a look.

Other AoA Caregiver Resources

The AoA home page's "Quick Index" chart takes web surfers to a "Caregivers Resources" page (www.aoa.gov/caregivers/default.htm) that in turn leads to several useful websites, including the **Eldercare Locator** (at 1-800-677-1116), which can help caregivers find services local to their care recipient.

This page also leads to the NAIC (**National Aging Information Center**) link to Caregiver Resources (www.aoa.gov/NAIC/Notes/caregiverresource.html), which leads in turn to many other useful sites:

- Many of the caregiver websites offer **practical guides or advice for family caregivers**, including the University of Buffalo at <http://www.acsu.buffalo.edu/~drstall/hndbk0.html>.
- Those looking for **written resources** should go to the National Alliance for Caregiving's Family Care Resource Connection searchable database of reviewed resources (www.asaging.org/nac/nactree.cfm). Searching for elder abuse, for instance, yielded 24 lengthy reviews of books, manuals, websites, and pamphlets that address some aspect of preventing or responding to elder abuse. Also well worth checking is Family Caregiver America's site (www.familycareamerica.com),

which has an extensive online library, including good materials on **long-distance caregiving**.

- Information on **caregiver support groups** is available in many places. The Well Spouse Foundation at www.wellspouse.org/ lists many in-person groups. An online support group is offered by the Family Caregiver Alliance at <http://www.caregiver.org>. A daily caregiver online "chat" is offered through www.carethere.com/.
- Information about **government programs and elder law** is available, among other places, at www.caregiverzone.com/.

The AoA website also leads to a collection of "Caregiving Resources for the Aging Network" at www.aoa.gov/carenetwork/default.htm. Useful information available here includes basic information on the Family and Medical Leave Act (which can help employed family caregivers get leave), an unvalidated caregiver stress quiz (at www.aoa.gov/carenetwork/PA-CGAssessmentFormsandInstructions.html), and the research review discussed below.

Caregiving Research Review

A good article for service providers who would like to get a better handle on how to support well-intentioned caregivers is "Family Caregiving in an Aging Society," located at www.aoa.gov/caregivers/FamCare.html.

This paper reviews the literature on caregiving with an eye to policy implications. One conclusion is that service providers should make a distinction between those who are caring for elders with dementia, and all other elder caregivers: levels of stress,

life disruption, depression, and illness are all much higher when dementia is part of the picture. The paper's author, Sharon Tennstedt, Ph.D., emphasizes the flaws in prior research indicating that caregivers from minority racial/ethnic groups experience less stress than White caregivers, explaining that minority caregivers are expressing their stress in ways that differ from what the researchers are measuring.

Studies reviewed in the article show that utilizing formal, paid services did not seem to lower caregiver stress. What *does* help is assisting caregivers to feel they have more control over their caregiving experience. "We found that a better quality of caregiver/care recipient relationship, a sense of mastery, and emotional support decreased the likelihood of role overload and, in turn, depression." ♣

NCEA Website Visitors:

January 2001: 3,174

National Family Caregiver Support Program Funded

The newest component of the Older Americans Act, the National Family Caregiver Support Program (NFCSP), received \$125 million in FY 2001 appropriations.

Thirteen states will each receive \$564,300 for NFCSP services; the balance will receive higher amounts based on the number of people in the state age 70 and older, ranging up to California's nearly \$11.5 million.

NFCSP funds will go to each State's Unit or Office on Aging. For states that have area agencies on aging (AAA), funds will then go to the AAAs. Five categories of services are authorized under NFCSP: 1) providing information about services available in the community; 2) providing assistance to caregivers who need help accessing those services; 3) individual counseling, caregiver training, and the organization and provision of support groups; 4) respite care; and 5) supplemental services. No more than twenty percent of the total federal funding for NFCSP can be spent in the category of supplemental services.

AoA will issue guidance to states on how to implement the NFCSP soon. ♣

Please Help Us Out

Have you developed a training manual, curriculum guide, publication or videotape? Does your state publish an annual APS report? Have you completed a report on a demonstration or research project? Share your materials with the Clearinghouse on Abuse and Neglect of the Elderly (CANE) so that others can learn from, and about, you. Please send a copy to CANE, Department of Consumer Studies, University of Delaware, Newark, DE 19716.

Book Reviews:

- ***Coping with Your Difficult Older Parent: A Guide for Stressed-Out Children***
- ***Another Country: Navigating the Emotional Terrain of Our Elders***
- ***Ending Elder Abuse: A Family Guide***

Although studies have found that caregiver stress is *not*, as previously thought, a major cause of elder abuse and neglect, the caregiving research detailed in "Family Caregiving in an Aging Society," (see article elsewhere in this edition) makes it clear that well-meaning caregivers do a better job – and help keep themselves out of the "high-risk for abuse or self-neglect" category – when they are able to improve their relationship with their care receivers, feel more sense of control, and find emotional support.

For that reason, NCEA staff reviewed two recent books specifically written to help adult children gain more insight and skills in dealing with "difficult" elders.

Grace Lebow and Barbara Kane are clinical social workers who specialize in providing case management services to elders and their families. Their book, *Coping with Your Difficult Older Parent: A Guide for Stressed-Out Children* (Avon Books, 1999), starts with a quiz that helps readers categorize the "type" of difficult elder they are working with. Chapters with headings like "When Your Parent Clings to You" and "Negative and Other Turn-off Behaviors" then describe these personality types, explain what kinds of experiences led to

their development, and recommend practical tips for dealing with these personality traits. Throughout the book, the authors stress that most of the time, these elders have always had a “difficult” personality and are very unlikely to change now. Therefore, they focus on what adult children can do to lower their negative reactions to the behavior, and to change their sides of familiar interaction patterns that may exacerbate the problem.

The book is easy to read, both because it uses various formatting styles to break the text into manageable pieces and because it makes extensive use of case studies and constructed dialogue. Although it is structured so that readers can focus solely on the personality type they are dealing with, reading all of the stories and advice may be helpful to those of us who have trouble shifting our focus from changing others’ difficult behaviors to changing our own reactions to those behaviors.

Therapist Mary Pipher’s *Another Country: Navigating the Emotional Terrain of Our Elders* (Riverhead Books, 1999) doesn’t pretend to be a practical guide for stressed-out adult children, although she periodically suggests conversation-openers and other interaction tips. Instead, the book seems more of a description of what Pipher has concluded about elders and baby boomers, and how she came to those conclusions.

For this reviewer, the most interesting section of the book was the first, “Landscape of Age.” It is here that Dr. Pipher sketches out the differences in values and experience between the current generations of elders and their baby boomer children and grandchildren. She describes current elders as growing up “pre-irony” and communal (and therefore from “a world in which all behavior mattered”). They were taught to keep their feelings to themselves. She says,

“When I began writing this book, I thought what would most separate my generation from earlier ones was technological change. But, in my experience, the ‘great divide’ turns out to be psychology.” The discussions and case studies in this section may be very helpful to adult children who are grappling with feelings that their parents aren’t grieving properly or are too concerned with what other people think.

Unfortunately, accompanying Dr. Pipher’s ability to discern generational patterns is a tendency to minimize differences within generations and a propensity for projecting her own issues onto others. Thus she is able to make statements like, “[t]he old lose their health and finally their hope,” and “[e]ach of us will experience our ship going down; we’ll experience being lost and far from home,” without wondering whether it is true that *all* of us will find dying to be a lonely, frightening process that must be fought against. Nevertheless, for those who are just beginning to think about elder issues, this book may be a good place to start.

The third book sounded immensely promising for caregivers trying to prevent abuse: *Ending Elder Abuse: A Family Guide: How You Can Protect Your Loved Ones, Evaluate Facilities, Partner with the Medical Community, Take Care of Yourself, Motivate Legislators and Government Officials, and What to Do if Things Go Wrong* (QED Press, 2000). Unfortunately, this book, written by Diane S. Sandell and Lois Hudson, oversells itself.

The most obvious failing is that the authors give virtually no attention to domestic elder abuse. When they mention such abuse, they dismiss it quickly with fallacies such as these: “In recent years, more media attention has been given to elder abuse; however, the major emphasis has been on

abuse in the home by a relative or hired caregiver. While there may be no witnesses to the abuse in the home, the fact of physical evidence and symptoms, as well as the presence and opportunity of the responsible person, often leads to prosecution.”

The other major failing is that the book is more memoir than guide. The majority of text is devoted to what happened to Mrs. Sandell’s mother, Bessie Lane, in two nursing homes, and how Mrs. Sandell came to terms with that abuse by founding NOBLE – Network Outreach – Better Living for the Elderly. Although such personal stories are useful in putting a “face” on elder abuse, the first-person storytelling in this book sometimes overwhelms the parts that are devoted to guidance for others.

Still, there is much to recommend the book. Sandell and Hudson see institutional elder abuse as a social problem requiring the attention of multiple professionals. They therefore have chapters on what families, physicians and medical personnel, nursing home administrators and corporate managers, and legislators and government officials can and should do. They advise on proactive steps family members can take to help prevent abuse or at least make it easier to prove if it does happen. They also include advice for caregivers of elders who are still in their own or their caregivers’ homes on topics like “coping with role reversal.” Finally, their community perspective leads them to include much information and advice on how to organize family councils and community elder abuse councils, and otherwise function as an advocate for more than just one’s own loved one. ♣

Community Coalitions Spotlight

Sonoma County (California) Elder Abuse Prevention Council

by Carol Downs

Since 1999 the Elder Abuse Prevention Council (EAPC) has provided the impetus and follow-through for the Area Agency on Aging Advisory Council’s action plan to increase public awareness through an education campaign on elder and dependent adult abuse.

Volunteers from Meals on Wheels and the Brown Bag Program have participated in EAPC sentinel elder abuse training on the signs of abuse and the protocol for reporting suspected cases of elder abuse. EAPC is working closely with Adult Protective Services and local law enforcement agencies to provide the sentinel training to volunteers both in the population centers of the county and in outlying areas.

With funding from the NCEA Sentinel Project, EAPC has produced two products that will enhance the Meals on Wheels and Brown Bag Program sentinel volunteers’ efforts: a placemat and a grocery bag. Each product includes information on the two types of elder abuse most prevalent in Sonoma County – paid caregiver abuse and financial exploitation -- and resource numbers for senior services. Distribution of 7,000 placemats and 5,000 grocery bags by the sentinel volunteers to homebound seniors is underway.

EAPC suggests that other elder abuse coalitions seeking to distribute similar products approach local fast food chains and grocery stores (McDonald’s, Burger King, Safeway, Albertson’s, etc.) to enlist their support in printing bags and placemats. ♣

Community Coalitions Tips

Committees to the Rescue

by Mary Twomey and Carol Downs

Starting an elder abuse coalition is not for the faint-hearted. Decisions need to be made concerning: member organizations; ground rules and interagency agreements; specific topics the coalition will prioritize; and strategies for gaining the attention of the community and media so a difference can be made. It can seem overwhelming.

To make the endeavor more manageable, many coalitions have found it helpful to break up the tasks by establishing committees to address various coalition functions. The initial challenge here is to determine what committees will be most effective in fulfilling the coalition's goals and objectives.

An Executive or Steering Committee might be established to determine the structure of the coalition; coordinate activities of the various committees and review their results; assure smooth communication among committees; prepare and oversee the budget; and be the mouthpiece for the coalition.

If professional education is a goal, a Professional Education Committee may be established to determine the gaps in elder abuse knowledge among professionals; develop appropriate training materials; decide where, how often, and by whom training sessions will be offered; and investigate opportunities for cross-training.

A Public Awareness Committee concentrating on outreach may develop surveys or other assessment instruments to determine public awareness of elder abuse; decide what activities would be most effective in

educating the public; identify community organizations that could be appropriate partners; develop effective ways of reaching at-risk elders; and launch a public awareness campaign.

A Media Committee may develop on-going relationships with local newspapers, radio stations and public television stations. It can look at a range of effective ways (PSAs, articles, videos, etc.) to get the "message" across and keep elder abuse prevention in the public spotlight. A member of the media may be a good coalition member to recruit for this committee.

A Public Policy Committee could monitor state and local laws and regulations that impact on elder abuse prevention programs; provide advice to legislators; and initiate legislation affecting elder abuse prevention and intervention programs.

Other examples of specific committees coalitions use include a Long Term Care Committee, a Minority Affairs Committee, a Victim Advocacy Committee, and a Legal Aid Committee. Key to committee success is linking committees to specific coalition objectives and matching coalition members to the committee(s) that can best utilize their skills. ♣

Newsletter editors: We encourage you to reprint or adapt these articles for your own newsletters. Please credit the National Center on Elder Abuse Newsletter.

Reaching the National Center on Elder Abuse (NCEA)

NCEA provides elder abuse information to professionals and the public; offers technical assistance and training to elder abuse agencies and related professionals; conducts short-term research; and assists with elder abuse program and policy development.

It is funded in part by the U.S. Administration on Aging and consists of a partnership of six agencies: the National Association of State Units on Aging (the grantee), the Clearinghouse on Abuse and Neglect of the Elderly, the Commission on Legal Problems of the Elderly of the American Bar Association, the National Association of Adult Protective Services Administrators, the National Committee for the Prevention of Elder Abuse, and the San Francisco Consortium for Elder Abuse Prevention.

NCEA's website contains many resources and publications to help achieve NCEA's goals. You can find the website at www.elderabusecenter.org. NCEA may also be reached by phone (202/898-2586); fax (202/898-2583); mail (1201 15th Street, N.W., Suite 350, Washington, D.C. 20005-2800); and e-mail (NCEA@nasua.org).



Elder Abuse Listserve Available

Craving more information and details about elder abuse issues and initiatives than a monthly newsletter can provide? Then you want the NCEA listserve!

The elder abuse listserve provides a *free* 24-hour, 7-day-a-week on-line linkage to others working on elder abuse issues. Subscribers "post" (e-mail) a question, announcement, or discussion topic to the listserv, which automatically distributes the message by e-mail to all the other subscribers. Whoever wants to reply can do so. Every subscriber sees all the posts unless two or more subscribers choose to take a particular discussion "off-list" and e-mail privately.

The listserv is for practitioners, administrators, educators, health professionals, researchers, law enforcement officers, judges, lawyers, and policy makers who are concerned about elder abuse. If that includes you and you have an e-mail address, it's easy to join. Contact the list manager (preferably by e-mail): Lori A. Stiegel, Associate Staff Director, ABA Commission on Legal Problems of the Elderly, 740 15th St., NW, Washington, DC 20005; phone: 202-662-8692, fax: 202-662-8698; <lstiegel@staff.abanet.org>.

Subscription requests must include each potential subscriber's name, e-mail address, profession, and an explanation of his or her interest in adult protective services/elder abuse.

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