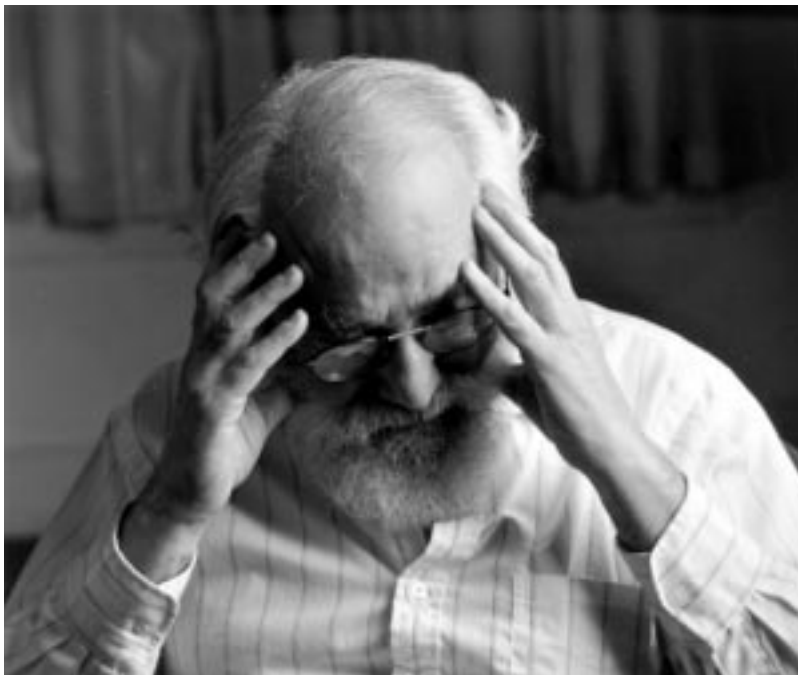


Preventing Elder Abuse



by Family Caregivers

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Caregiver Stress and Elder Abuse

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NCEA exists to provide elder abuse information to professionals and the public; offer technical assistance and training to elder abuse agencies and related professionals; conduct short-term elder abuse research; and assist with elder abuse program and policy development. NCEA's website contains many resources and publications to help achieve these 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); and email (NCEA@nasua.org).

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Introduction

Researchers and practitioners in the field of elder abuse prevention have long assumed that the stresses associated with caring for impaired family members, particularly those with dementias, trigger abuse or neglect. The relationship between caregiving, caregiver stress and abuse has, however, remained poorly understood.

Early studies portrayed the “typical” elder abuse case as one in which a frail older woman was abused by a well-meaning but understandably overstressed caregiver. Some researchers and professionals in the fields of elder abuse prevention and adult protective services have blamed this persistent characterization, now known to be inadequate, with distorting the public’s understanding of elder abuse and steering attention away from more promising lines of inquiry. Some believe that this profile accounted for the fact that elder abuse was viewed for many years strictly as a social service problem that could be addressed most effectively through social service interventions; today, many forms of abuse and neglect are resolved through legal interventions as well.



From the other end, professionals in the field of dementia care have tended to de-emphasize violence in caregiving relationships, and hesitated to apply the label of elder abuse to mistreatment by family caregivers. It is understandable that some view elder abuse as an inadequate description for the complex dynamics and interactions that often accompany aggression in caregiving relationships, particularly when the aggression is mutual or interactive. Some fear that focusing on caregivers’ aggression, without considering the broader context in which it occurs, may lead to unfair punitive responses.

These divergent views and interests may account for the current lack of coordination and collaboration between the elder abuse prevention network and that which serves caregivers. This is regrettable in light of the wealth of knowledge, insight and resources that the two networks potentially have to offer one another. This manual was designed to improve the situation by exploring the interface between caregiving, stress and elder abuse, and the networks that serve caregivers and abuse victims. It further attempts to pave the way for better coordination between the two networks.

Part 1 describes caregiving and presents profiles of caregivers. It further describes the stresses that some informal caregivers experience and the wide variations among caregivers in how they perceive their roles and cope with stress.

Part 2 explores current understanding of the relationship between caregiver stress and physical elder abuse. It highlights the importance of caregivers’ past and present relationships with care receivers and their fears about becoming violent.

Part 3 describes community services that are available to ease caregivers’ stress and those that were specifically designed for high-risk caregivers. Recommendations for how professionals, agencies and the health care system can respond more effectively to caregivers’ needs are also offered.

Part 4 describes resources available to caregivers and professionals. It emphasizes how the Internet has become a significant source of support and information.



Part 1: Caregiving and Caregiver Stress

An Overview of Caregiving

The term “caregiver” refers to anyone who routinely helps others who are limited by chronic conditions. “Formal caregivers” are volunteers or paid employees connected to the social service or health care systems. The term “informal caregiver” refers to family members and friends, who provide nearly three-quarters of the care currently being provided to impaired older adults living in the community. “Long distance caregivers” refers to people who are involved in providing care to older friends or family members they are geographically separated from.

Although people with any type of disability may need assistance, and care can be provided in any number of settings, the literature on caregiving has tended to focus on the challenges of providing care to persons with cognitive impairments, particularly Alzheimer’s disease, in their homes. This may be attributed to the high level of care these patients often require, and the highly stressful nature of caring for people with cognitive impairments (Tennstedt, 1999).

The tasks for which assistance is typically needed are classified into two categories. “Activities of Daily Living” (ADLs) include bathing, dressing, getting

in and out of bed and chairs, and using the toilet. “Instrumental Activities of Daily Living” (IADLs) include housework, grocery shopping, preparing meals, arranging for outside services, and managing finances and medications. The most frequently provided forms of assistance are household chores, meal preparation, and personal care such as dressing, bathing and toileting. The type and amount of care that caregivers provide is influenced by several factors including the relationship of the caregiver to the care receiver, whether the caregiver and care receiver live together, and the family’s race and ethnicity.

Profiles of caregivers have been relatively consistent in the literature (Tennstedt, 1999; National Alliance for Caregiving and the American Association of Retired Persons, 1997). One family member typically serves as the “primary caregiver,” and others serve as “secondary caregivers” (Montgomery and Kosloski, 2000). Spouses are most likely to be primary caregivers (48 percent) and the majority (72 percent) are women. Spousal caregivers also provide the most extensive and comprehensive care (between 40 to 60 hours a week). When a spouse is not available to provide care, the responsibility typically falls to a daughter. In the absence

of a daughter, a son may become the primary caregiver, although there is evidence to suggest that sons often pass along caregiving responsibilities to their wives. Caregiving children report that they spend 15 to 30 hours a week providing care, and they tend to concentrate their caregiving hours on managing care and assisting with transportation and shopping. The remaining caregivers include more distant family members and friends. Caregiving responsibilities are also likely to be assumed by family members who have fewer competing demands on their time than others in the family.

Which family members become caregivers and the type of care they provide are also influenced by cultural factors (Montgomery and Kosloski, 2000). Among Blacks and Hispanics, adult children are much more likely to be primary caregivers — 75 percent of caregivers are adult children. This has been attributed to the fact that minority women are more likely to be single. The daughters of minority elders provide more household and personal care than Caucasian daughters. Researchers have noted that care receivers' needs change as their illnesses or disabilities progress. In the early stages of caring for dementia patients, for example, caregivers take over high-level activities like financial management, driving and shopping. As the disease progresses, they assist with more basic tasks like dressing and eating. As the impairment becomes more severe, caregivers take on heavier nursing care such as managing incontinence and avoiding pressure sores. Care may be needed 24 hours a day.

The concept of a "caregiver trajectory" has been proposed to explain the changing context in which caregiving occurs and caregivers' changing perceptions about their roles (Montgomery and Kosloski, 2000). According to this explanation, factors such as the type and level of impairment that the care receiver exhibits, the stability of the care receivers' functioning level, and the physical and social environment all influence caregivers' needs, their levels of distress, and the likelihood that they will continue to provide care. Seven markers have been identified along

the caregiving trajectory. The first is reached when a caregiver initially begins to perform caregiving tasks; subsequent markers include (2) the point at which the individual comes to view himself as a caregiver; (3) the caregiver begins to provide personal care; (4) the caregiver actively seeks out formal support services; (5) the caregiver considers placing the elder into a nursing home; (6) the nursing home placement occurs; and (7) the termination of the caregiver role.

The Negative Consequences of Providing Care

Although many informal caregivers find caregiving to be emotionally satisfying and personally enriching, caregiving has negative consequences for some. In recent years, significant attention has been directed toward understanding the impact of caregiving on caregivers' personal and social well-being, and their health. Specific factors that have been looked at include the physical and emotional health indicators associated with stress, which include depression, sick days and health care utilization. Although early studies focused on all caregivers, regardless of the disabilities of the patients they cared for, more recent studies have distinguished between the experiences of persons caring for elders with dementing illnesses and elders with other types of disability.

Depression and anxiety appear to be significant problems for all caregivers (Tennstedt, 1999). The rate of depression for non-dementia caregivers is 35.2 percent, which is twice that of the general population. Among dementia caregivers, this rate has been found to be as high as 43 – 46%.

Common physical complaints reported by caregivers include lack of sleep and inadequate exercise and nutrition; these problems are attributed to patients' (especially dementia patients') disturbed sleep patterns or their need for constant supervision. Studies to substantiate the impact of caregiving on caregivers' health have, however, yielded inconsistent findings.

Significant attention in recent years has been directed toward understanding caregivers' stress. Stress

is frequently described as the body's "fight or flight" response to danger or trauma. According to this explanation, the brain goes on "high alert," causing respiration and heart rate to speed up in order to provide the body with the extra oxygen and nutrients it needs. Glucose is released into the blood and blood pressure rises as vessels to less critical parts of the body constrict. The immune system shuts down. Cholesterol and triglyceride levels become elevated. Common physical indicators of stress include dry mouth, headache, confusion, nightmares, indigestion, skin problems, clammy hands, tearfulness, feeling faint, eating disorders, diarrhea or constipation, nausea, heart palpitations and fatigue. The term "burnout" describes caregivers' physical, emotional and mental exhaustion.

Although the stress response is a healthy reaction to danger, the body needs to repair itself once danger is removed. For caregivers, whose stress often results from fatigue and conflicts that never go away, their bodies never get a chance to heal. Because the immune system stays shut down, caregivers are at increased risk for infections and disease. Similarly, their blood pressure may remain high and their arteries constricted. They may experience decreased blood flow to the heart. Stress is believed by some to cause hypertension and to play a role in silent ischemia and coronary disease. The "Caregiver Health Effects Study" (Schulz and Beach, 1999) revealed the shocking finding that caregivers who experienced the greatest levels of stress were 63 percent more likely to die within the next 4 years than non-caregivers.

What Causes Caregiver Stress?

Caregiver stress is a complex phenomenon. Early studies typically explained it in relation to caregivers' "burden"; burden was defined in terms of patients' level of disability and the extent of care they required. According to this explanation, the greater the disability, the more care is required and the greater the stress on the caregiver.

It has further been assumed by some that stress is associated with the type of care provided,

which varies according to the care receiver's illness and its progression. As described earlier, in the early stages of caring for dementia patients, caregivers take over high-level activities like financial management, driving and shopping; as the disease progresses, they assist with more basic tasks like dressing and eating. It is during this middle phase that patients engage in potentially dangerous and disruptive behavior such as wandering and combativeness. As the impairment becomes more severe, these problems diminish but caregivers take on heavier nursing care such as managing incontinence and avoiding pressure sores.

Studies that attribute caregiver stress to burden, however, fail to account for the fact that some caregivers with heavy loads experience little stress, while others, with fewer demands, experience high levels of stress. This observation has prompted several researchers to explore subjective factors. Some have looked at caregivers' personality traits or attitudes, including how they perceive and react to caregiving. Others have looked at the dynamics between caregivers and receivers prior to and subsequent to the onset of disability (often referred to as "premorbid" and "postmorbid" relationships). Still others have focused on specific behaviors or circumstances that cause distress and caregivers' ways of coping.

It is now known that caregivers' stress levels are affected, to a great extent, by how they feel about their caregiving responsibilities and the people for whom they provide care (Zarit and Toseland, 1989). Stress levels are greatest for caregivers who report that they feel overwhelmed, guilty, constantly in demand or "out of control." Those who feel they receive inadequate support from other family members also report higher levels of stress. Caregivers who perceive the patients they care for as manipulative, unappreciative or unreasonable also report higher levels of stress and strain.

Several studies have revealed that caregivers find certain behaviors of care receivers to be particularly stressful (Quayhagen, et al, 1997; Deimling and Bass, 1986; Compton, Flanagan, and Gregg, 1997). These

include patients' lack of impulse control, volatility, anger, self-absorption, inability to show enthusiasm, poor concentration, paranoia, withdrawal, aggression, repetition of words or actions, bizarre behavior resulting from hallucinations, severe mood swings, verbal or physical aggression, combativeness, wandering, incontinence, sleeplessness and "sundowning" (the tendency for patients' mental functions to decrease through the course of the day). Aggression and violence have emerged as primary causes of stress for caregivers. Researchers have noted that violence and aggression are most likely to occur while caregivers are providing personal care that requires physical contact, such as bathing or dressing (Ware, Fairburn, and Hope, 1990).

The nature of the premorbid relationship between caregivers and care receivers has also been found to be significant in predicting stress (Hamel et al, 1990). Caregivers who had positive relationships with patients in the past report lower levels of stress even when the demands of caregiving are extremely high.

The likelihood that caregivers will experience stress and their level of stress also depend on caregivers' coping ability and the types of coping strategies they use (Tennstedt, 1999; Quayhagen, et al; Bendik, 1992). A study by the National Alliance for Caregiving and the American Association of Retired Persons (1997) reported that the most common methods of coping used by caregivers were prayer (74 percent), talking with friends or relatives (66 percent), exercise (38 percent), hobbies (36 percent), and seeking professional help or counseling (16 percent). Most caregivers used multiple coping mechanisms. Maladaptive coping includes avoidance, smoking, drinking or over-eating.



Part 2: Caregiver Stress and Elder Abuse

Although the overwhelming majority of informal caregivers provide adequate to excellent care, reports of abuse are not uncommon and appear to be on the rise. Abuse by caregivers may be physical, emotional or financial. It may involve intentional or unintentional neglect. These various forms of abuse may be motivated by many factors. The motive behind financial abuse and intentional neglect, for example, is often greed. Domestic violence by a caregiving spouse or intimate partner is motivated by the abuser's need to exercise power and control. Abuse by caregivers may be triggered or exacerbated by alcohol or substance abuse, or psychiatric illness.

Although all of these forms of abuse by caregivers are of critical concern, this publication focuses on caregiver abuse that is related to the stresses associated with caregiving. Financial abuse and domestic violence by caregivers, and the relationship of substance abuse to elder abuse are addressed in other publications produced by the National Center on Elder Abuse. Further, although caregiver stress is believed by many to cause other forms of abuse, including neglect and psychological abuse, there has been little research on the relationships between these factors. Consequently, the focus of the following section is on the relationship between caregiver stress and physical elder abuse.

Caregiver Stress and Physical Abuse

Studies of physical abuse by caregivers have yielded divergent results reflecting variations in methodology and how caregiving was defined (Wolf, 1996). An early study of abuse by non-spousal caregivers, for example, revealed that 23 percent engaged in some form of physical abuse. A survey administered to a sample of 342 callers to a help line for caregivers found that 12 percent of the callers had physically abused the person in their care at least once (Coyne, Reichman, and Berbig, 1993). Other studies have revealed rates of physical abuse by caregivers at 6 percent (Pillemer and Suiter, 1992), 5 percent (Paveza, et. al., 1992), and 10.5 percent (Compton et al, 1997).

Other inconsistencies have also been observed. For example, one research team identified adult offspring caregivers as the most likely to commit acts of violence (Paveza et al., 1992); others suggest that spousal caregivers are proportionately more likely to abuse (Pillemer and Suiter, 1992).

Assuming that caregiver abuse is related to caregiver stress, several researchers have attempted to discern whether or not the predictors of stress also predict abuse. This line of reasoning has yielded some promising results. Depression, which is highly predictive of caregiver stress, has also been found to be a

strong predictor of elder abuse, particularly when caregivers' level of depression reaches near-clinical levels (Paveza et al., 1992; Coyne et al., 1993). Similarly, cohabitation has been found to be highly predictive for both caregiver stress and caregiver abuse (Pillemer and Suiter, 1992), although some suggest that this is only true in cases of non-spousal caregiver abuse (Paveza et al., 1992).

Several researchers who have taken a closer look at the process by which caregiver stress turns to violence have observed intervening factors or links between stress and violence. Bendek and his colleagues (1992), for example, postulated that stress, in and of itself, does not cause caregivers to become abusive; rather, it leads to "mood disturbances," which may lead to abuse. When caregivers lack adequate income, problem-solving skills or social support, or when they believe that the situation is beyond their control, it triggers a sequence of events that lead to mood disturbances and a loss of rational behavior. It is these mood disturbances that culminate in mistreatment. Garcia and Kosberg (1992) identified anger as the intermediary step or link between stress and abuse.

Just as the early literature on care-giving assumed that stress was directly related to burden (defined in terms of care receivers' disabilities and the amount of care they require), early researchers in elder abuse also assumed that the risk of abuse increased in direct relation to the amount of care required. There is some evidence to support this assumption. Coyne and his colleagues (1993) observed, for example, that the risk of abuse is elevated when caregivers provide high levels of care (defined in terms of hours of care per day and the number of years that care is provided), and that victims function at lower levels than their non-abused counterparts (Coyne, 1993). However, other studies of caregiver abuse have mirrored the literature on caregiver stress in suggesting that these objective measures of burden are less important than subjective factors. Some, in fact, believe that victims of caregiver abuse are no more impaired and require no more care than non-abused care receivers (Pillemer and Suitor,

1992). Many now believe that it is the quality of past relationships between caregivers and care receivers, caregivers' perceptions of burden, and caregivers' patterns of coping that explain why stress leads some caregivers, but not others, to abuse.

Just as caregivers who have had close and positive relationships with patients in the past are less likely to experience stress, so too are they less likely to become violent. It has also been observed that care receivers who were violent toward their caregivers prior to the onset of their illnesses, are more likely to suffer abuse at the hands of their caregivers (Coyne et al, 1993; Hamel et al, 1990).

The likelihood that caregivers will abuse also appears to be strongly linked to how they perceive their situations. Abusive caregivers are more likely than non-abusive caregivers to feel that they aren't receiving adequate help from their families, social networks or public entities (Compton et. al, 1997; Anetzberger, 1987). Anetzberger (1987) found that these perceptions may be ungrounded. Abusive caregivers who perceived themselves to be socially isolated, for example, were not, in fact, found to be more isolated than their non-abusive counterparts when objective measures of isolation were employed.

Abusive caregivers report that certain behaviors are particularly stressful to them. These include verbal aggression, refusal to eat or take medications, calling the police, invading the caregiver's privacy, noisiness, "vulgar habits," disruptive behavior, embarrassing public displays and physical aggression (Compton et al, 1997; Pillemer and Suitor, 1992; Anetzberger, 1987).

Caregivers' low self-esteem has also emerged as a significant risk factor in predicting abuse, although, as some researchers point out, the causal relationship between abuse and self-esteem is not clear (Pillemer and Suiter, 1992). It has not been determined whether low self-esteem is the cause or the result of abuse.

“Families at Risk” and Interactive Violence

Whereas patient aggression and caregiver abuse have, in the past, been viewed as separate and unrelated phenomena, the two are increasingly being seen as interrelated. Several researchers have proposed that caregiving creates stresses that affect both caregivers and patients, and that these stresses may trigger aggression in one or the other partner, or both. Some even suggest that a more useful approach to understanding the risk of abuse in caregiving relationships is to look at “families at risk,” as opposed to individuals at risk.

Studies of families at risk have looked at pairs, or “dyads,” of caregivers and care receivers in which one or both members are abusive. These studies have revealed that caregivers in abusive dyads report higher levels of emotional and mental burnout, poorer physical health, and stronger reactions to care receivers, regardless of whether it is the caregiver or the care receiver who is violent (Quayhagen et al, 1997). Depression and living together have been found to be predictive of abuse in either direction (Paveza et al, 1992). Paveza and his colleagues further suggest that when abuse is mutual, which they found to be the case in 3.8 percent of the families, it reflects a reactive pattern or feedback loop between caregivers and patients; patients’ verbal and physical abuse prompts caregivers to abuse (Paveza et al, 1992).

Fear of Becoming Violent

The research on caregiver stress and abuse has revealed that a surprisingly high proportion of caregivers (20 percent) live in fear that they will become violent. This rate increases to 57 percent among caregivers who have experienced violence from those they care for (Pillemer and Suitor, 1992). The fear of becoming abusive also appears to be affected by living arrangement. Caregivers who live with care receivers are more likely to experience fear, particularly when the caregiver is a spouse and the marital relationship has been stressful. Fearful caregivers have also

been found to have lower self-esteem and to be older (Pillemer and Suiter, 1992) than non-fearful caregivers.

Pillemer and Suiter (1992) went further in exploring whether the fear of becoming abusive actually leads to or predicts violence. In looking at 236 caregivers, they found that 14 percent feared they would become violent. Of these, 6 percent actually engaged in violent behavior. When fearful, non-abusive caregivers were compared with fearful abusive caregivers, several differences were observed. The violent caregivers were more likely to have experienced violence from care receivers, leading the researchers to conclude that “violence by care receivers is not only a risk factor for fear of violence but also appears to move persons who are fearful of becoming violent to actually commit violent acts.”

Non-Physical Abuse Associated with Caregiver Stress

Although it has been assumed by many that caregivers who experience high levels of stress may engage in other forms of mistreatment (besides physical abuse), only a few studies have looked at the relationship between stress and non-physical abuse. An early study on elder abuse (Steinmetz, 1988) suggests that one in 6 caregivers resort to emotional or psychological abuse and about one-third use verbally abusive methods to gain control. Compton (1997) estimated that as many as 26.3 percent of caregivers were verbally abusive (Compton, 1997). Neither study, however, established a direct link between stress and abuse. An Australian study on stress, coping and abuse (Rahman, 1996), in which 30 female caregivers were interviewed, revealed that some caregivers “felt so helpless that it made them lose their power of concentration, leading to accidents” (e.g. falls). According to Rahman, however, these caregivers did not feel responsible for the accidents or blame themselves.



Part 3: Services for Caregivers

Services and Techniques for Reducing Caregiver Stress

As the population ages and caregiving becomes a fact of life for many families, a myriad of new services have been developed to meet caregivers' need for support and assistance. These programs and services have been designed to help caregivers and their families reduce their stress and isolation, handle difficult behaviors, improve their coping skills, and delay or prevent nursing home placement. Services for caregivers are typically funded by states through general revenue funds or as part of multipurpose, publicly-funded home and community-based care programs that serve both care recipients and their family caregivers.

Fifteen states now have comprehensive state-funded caregiver support programs, which typically offer respite care and 4 or more other services, including specialized information and referral, family consultation or care planning, support groups, care management and education and training (Coleman, 2000). The states vary considerably in how they deliver and fund these services, and how they define eligibility. Other states have developed smaller, innovative programs.

Policymakers at the national level are increasingly recognizing the needs of caregivers. The Older Americans Act Amendments of 2000 established an

important new program, the National Family Caregiver Support Program (NFCSP), which will increase the supply of support services available to informal caregivers (information on these services is available on the Administration on Aging's website at <http://www.aoa.gov/carenetwork/default.htm>). Among the many services that are now commonly available to caregivers are the following:

Support Groups

Organized by public and private agencies, groups provide social support, information, instruction in how to handle difficult behaviors, and assistance in working through the negative feelings that family caregivers may have toward their roles. Some help caregivers understand their own stress "triggers," and develop techniques for reducing stress.

Education

Countless materials, fact sheets, brochures, articles, courses and websites provide information and training to caregivers. Learning about the symptoms, progression, prognosis and treatment of diseases can relieve caregivers' uncertainties, enable them to identify problems with medications, and reduce the common tendency to take disturbing behaviors personally.

Assessments

Assessments are used to develop comprehensive plans for meeting care receivers' needs and addressing problems. They range from simple checklists to comprehensive geriatric assessments performed in hospitals and clinics by teams of medical and social work professionals. Specialists, including speech therapists, occupational therapists, geropsychiatrists, physical therapists and others, assess patients' deficits and disabilities. They then educate families about patients' needs, offer advice and referral information, and instruct families in how to manage behaviors or provide appropriate care.

Case Management

Case management is a model for providing services that was developed for persons with multiple and changing service needs. Case managers perform comprehensive "functional assessments" in which they evaluate the client's ability to perform daily tasks. Following the assessment, case managers frequently meet with other professionals to help develop multidisciplinary service plans that match clients' needs with available services. They then arrange for and monitor services, intervene in problems, and conduct routine reassessments to identify changes and circumvent crises.

Instruction in Behavior Management Techniques

As described in Parts 1 and 2, studies have identified a wide range of behaviors and situations that caregivers (both abusive and non-abusive) find particularly stressful and exhausting. These include wandering, personality changes, paranoia and aggressive behavior. A variety of techniques, materials, classes and groups have been developed to instruct caregivers in techniques for managing conflict and responding appropriately to difficult behaviors. Because troubling behaviors often arise from care receivers' frustration, pain or discomfort, caregivers can learn how to recognize what care receivers are experiencing so that they can respond appropriately.

Respite

Respite means rest or relief. There are a variety of approaches or models for providing relief. Some programs provide volunteers or employees who come to patients' homes for a few hours at a time to give caregivers a break. Others bring patients to agencies or special centers for several hours to participate in social, recreational or therapeutic programs. Still others offer placements in residential care facilities, hospitals or nursing homes for several days at a time to give caregivers extended breaks.

Formal Support Services

A variety of services are available to help reduce the demands on caregivers. Support services include personal assistance services, home delivered meals, escort services, home modification services and day programs. Friendly visitors and telephone reassurance programs can also reduce isolation, provide social contact and emotional support, and relieve anxiety.

Health Promotion

Many programs and informational materials for caregivers focus on the importance of good health in reducing stress. They describe stress reduction techniques such as relaxation exercises, proper diet and exercise.

Legal and Financial Planning

Planning for the future can reduce uncertainties about the future, preserve families' financial resources, and avoid crises. Helpful services include public benefits counseling, estate planning and assistance with advance directives.

The Challenges of Providing Services to Caregivers

Designing services for caregivers presents challenges to program planners. Understandably, the demands of caregiving prevent many caregivers from attending support groups, meeting with counselors, or even reading informational materials

because they lack the time or backup needed to do so.

Financial considerations may create additional barriers. Services such as geriatric assessments and case management can be expensive, and the demand for publicly-funded programs exceeds the supply in many communities. Depression, which is common among caregivers, may prevent some from seeking help.

Fortunately, new and creative solutions to these problems are emerging on an almost daily basis. For example, the Internet offers countless services designed for caregivers with limited time and backup. These include “virtual” support groups, informational websites and on-line consultation services. Other services designed for caregivers include toll-free telephone “help lines,” and mobile adult day care services in rural areas.

Services to Reduce the Risk of Abuse by Caregivers

Despite this growth in new programs for caregivers, little attention has been paid toward assessing or responding to the special needs of abusive caregivers or those at risk of becoming abusive. Furthermore, providers of protective services, who have traditionally focused on serving victims, rarely offer services to abusive caregivers or refer them to other agencies that do (Vinton, 1992).

These observations are particularly disturbing in light of the fact that victims of violence by caregivers are at significantly higher risk of being placed in nursing homes than victims of physical elder abuse by non-caregivers. Vinton (1992) compared service plans developed by protective service workers for members of both groups and found that 22 percent of the plans developed for victims of caregiver violence included nursing home placement, compared to only one percent of the plans developed for victims of violence by non-caregivers. Placement was, in fact, the most frequently recommended intervention in these cases, followed by adult day health care. Vinton also noted that even though a high proportion of abusers had substance abuse problems (25 percent of abusive

caregivers and 34 percent of abusers who were not caregivers), only 3 percent of the plans that were reviewed included alcohol or substance abuse treatment. Vinton suggests that this omission might be explained by the dearth of available substance abuse treatment programs as well as the fact that protective service providers typically focus on the needs of victims as opposed to abusers.

This inattention to the needs of caregivers who are at risk of becoming abusive points to the need for better coordination between agencies that provide protective services to victims and those that offer services to reduce caregiver stress. This need was acknowledged by service providers in the Cleveland, Ohio area, who noticed that few cross-referrals were being made between local Alzheimer’s Associations and adult protective service programs. After convening several meetings to find out why, representatives from the two networks collaborated to design referral protocols aimed at improving communication and promoting cooperation. A cross-training curriculum was also designed, which instructs protective service workers in dementia, functional limitations, techniques for managing difficult behaviors, and caregiver services. Conversely, it instructs personnel from Alzheimer’s Associations in how to recognize the signs and symptoms of elder abuse, how to make abuse reports, and how to access protective service resources. A self-assessment tool was designed to help caregivers recognize their own stress triggers and reduce their risk of becoming abusive or neglectful (See Section 4).

Scogen and his colleagues in Alabama (Scogen et al, 1989) developed and evaluated a training program for caregivers who were identified as being at risk for becoming abusive. The project was based on the assumption that increasing caregivers’ knowledge about aging and improving their coping and problem-solving skills, would reduce their stress and their risk of abusing. The training program contained content on the aging process, problem solving, stress and anger management, and community services. The researchers evaluated participants before and after the trainings for

signs of risk, including psychiatric symptoms, self-esteem, anger and perceived degree of burden. Despite some reductions in psychiatric symptoms, including headaches, insomnia, suspiciousness and anxiety, little improvement was observed. The researchers cautioned, however, that their failure to demonstrate greater impact might be accounted for by the fact that the caregivers' levels of risk were not particularly high to begin with. These caregivers exhibited only moderate levels of anger and relatively high self-esteem. The researchers further recommended that additional testing be completed with caregivers who had actually engaged in abusive behavior.

The value of social support in reducing the risk of caregiver abuse has also received attention. Researchers have observed that support networks can reduce caregiver violence and the fear of becoming violent. It appears that the effectiveness of these networks, however, depends on the type of support that is provided. To relieve stress and reduce the fear of becoming abusive, social support must come from others who have caregiving experience. Although support groups have been shown to be effective in raising members' sense of confidence and feelings of competence, they only decrease the fear of becoming violent for members who develop significant relationships with other members of the group (Pillemer and Sutor, 1992; Kilburn, 1996).

What Communities Can Do

As the relationship between caregiver stress and elder abuse becomes better understood, it has significant implications for the fields of caregiving, elder abuse prevention and adult protective services. This knowledge has provided insight into the dynamics between caregivers and care receivers, and has increased understanding of how factors such as depression, aggression, fear of becoming abusive, longstanding conflict and low self-esteem contribute to abuse. It has further suggested promising new directions and approaches to prevention and treatment.

Benefiting from this work, however, requires that protective service workers and professionals who work with caregivers achieve greater familiarity with each other's approaches, resources, interventions and outlooks. Protective service providers need to understand dementia and the care needs of patients, the pressures associated with caregiving, the relationship between stress and violence, and techniques for reducing stress. They need to become familiarized with resources that are available to caregivers and how to access them, so that they can develop more comprehensive plans that eliminate the need for more costly interventions, such as shelter, nursing home care or paid caregivers.

Professionals in the field of caregiving need to understand the relationship between caregiver stress and abuse so that they can recognize high-risk situations and respond appropriately. These professionals stand to benefit from improved coordination and collaboration with protective service professionals by enabling them to access protective service resources. Collaborating with protective service workers offers these professionals needed leverage to hold resistant, abusive caregivers accountable. Finally, the two networks share common goals that could be pursued more effectively through collective advocacy, cooperation and collaboration.

Vulnerable seniors and their caregivers also stand to benefit from better coordination and cooperation between the two networks. When agencies that serve caregivers work in concert with those that are charged to protect care receivers, the result is a more holistic approach that addresses the root causes of violence, minimizes rather than exacerbates tensions, supports family caregiving systems, and holds caregivers accountable.

The following recommendations are offered to stimulate further discussion about how abuse and neglect by caregivers can be prevented:

Recommendations

Agencies that Serve Caregivers can prevent abuse by caregivers through the following actions:

- Provide training to their staff in:
 - The relationship between elder abuse and caregiver stress
 - Statutory requirements for reporting abuse and how reports are investigated and responded to
 - Services and resources offered by protective service programs
- Adapt existing clinical assessment protocols to “red flag” the following high risk factors and situations:

The caregiver:

- Fears that he will become violent
- Suffers from low self esteem
- Perceives that she is not receiving adequate help or support from others
- Perceives caregiving responsibilities as a burden
- Is experiencing emotional and mental “burn-out,” anxiety or severe depression
- Feels “caught in the middle” by providing care to children and elderly family members at the same time

The care receiver:

- Is aggressive or combative
- Is verbally abusive
- Exhibits disturbing behaviors

The caregiver and the care receiver:

- Live together
- Had a poor relationship prior to the onset of the illness or disabling condition
- Are married and have a conflicted marital relationship

- Develop new (or adapt existing) counseling programs to address the emotional or mental health needs of abusive or high-risk caregivers, or make referrals to other agencies that can address these needs. Programs may provide group or individual counseling that addresses:
 - Depression and low self esteem
 - Current and past conflicts between family members
 - Caregivers’ expectations of care receivers
 - Caregivers’ expectations of themselves
 - Negative attitudes about caregiving
 - Alcohol and substance abuse
 - Fear of becoming abusive
- Develop or adapt existing education programs to focus on the following:
 - Community services, how to access them, and resources to pay for them
 - Techniques for responding effectively to care receivers’ disruptive and aggressive behaviors, including violence, combativeness and embarrassing public displays
 - How to determine the need for long term care services
 - How to select and monitor long term care providers and facilities
 - How to hire and supervise formal caregivers
 - Empowering care receivers to participate in decision-making about their care

Providers of Aging and Protective Services to the elderly and disabled can prevent caregiver abuse through the following:

- Provide training to personnel in the following areas:
 - Dementia, including its causes, treatment, prognosis and symptoms
 - Resources for assessing and treating dementia

- Caregiving issues, including the challenges of providing care, the impact of caregiving, stress reduction techniques, conflict resolution and techniques for effectively responding to difficult behaviors
 - The relationship between elder abuse and caregiver stress, including risk factors for abuse by caregivers
 - Resources available for caregivers
- Adapt protective service risk assessment tools to include the risk factors associated with caregiver abuse (see above).
- Establish policies and protocols aimed at improving coordination and communication with programs that serve caregivers. These should include provisions for collaborative investigations, assessments and care planning when appropriate (e.g. when aggression is mutual or interactive).

Program Planners, Policy Makers, and Advocates can reduce risk and improve the response to high-risk families through the following:

- Promote the development of the following support services:
 - Support groups
 - Respite
 - Volunteer programs to provide respite and support services such as shopping, transportation and friendly visits
 - Affordable home care services
 - Legal and financial planning services
- Increase the availability of respite care and other social support services through the following:
 - Expand existing programs for caregivers
 - Encourage employers to assist in providing relief to family caregivers
 - Offer tax relief to family caregivers

Researchers can contribute to current understanding of caregiver stress and its relationship to abuse through the following:

- Improve the reliability and validity of studies on the relationship between caregiver stress and elder abuse by:
 - Increasing sample sizes
 - Using in-person interviews of caregivers and patients whenever possible
 - Using case control studies followed by longitudinal studies
- Conduct research into the following areas:
 - Caregiver stress and neglect
 - Caregiver stress and psychological abuse
 - Caregiver stress and financial abuse
 - The nature of the caregiving relationship
 - The effectiveness of services (including group and individual counseling, respite, and education) in reducing caregiver stress and abuse
 - Effective coping strategies

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Part 4: Resources

NATIONAL ORGANIZATIONS

Alzheimer's Association

The Alzheimer's Association is the largest national voluntary health organization committed to finding a cure for Alzheimer's disease and helping those affected by it. State and local chapters provide services to people with the disease, their families and caregivers, and health care professionals. Local chapters respond to the needs of the communities they serve; their activities may include funding local research, assisting Alzheimer's patients who live alone, conducting multicultural and rural outreach, promoting service coordination and conducting or sponsoring training programs for families and professionals.

The association also provides research grants to explore the causes of the disease, treatment and prevention. Grants are also available to provide education and support to patients, their families and caregivers. The association publishes a variety of materials including resource directories, instructions in behavior management, information about the disease and its treatment, and training curricula. Its website contains sections for persons with the disease, caregivers, health care professionals, researchers and the media. For more information, contact:

Alzheimer's Association

919 North Michigan Avenue, Suite 1100
Chicago, Illinois 60611-1676
Telephone: 800.272.3900 or 312.335.8700
Website: <http://www.alz.org>



Family Caregiver Alliance

Family Caregiver Alliance is a national information center and a pioneer in the development of caregiver services. FCA serves as the lead agency in Link2Care, a program designed to provide Internet services to caregivers of adults with cognitive impairments. Once families are enrolled in the Link2Care program, they have access to a secured website, which offers a decision-support program; an information library; consultation with experts in medicine, law and related fields; moderated support groups; and a database of local community resources. FCA's website provides a wealth of information and online services to caregivers, policy-makers, the media and the public. For more information, contact:

FCA

690 Market Street, Suite 600
San Francisco, CA 94104
Telephone: 415.434.3388
Website: www.caregiver.org
Email: info@caregiver.org

AARP

AARP, the nation's leading organization for people over the age of 50, has produced a variety of publications on caregiving issues. A special section on its website (<http://www.aarp.org/indexes/life.html#caregiving>) offers useful information for caregivers including the guide referred to above and sections on financial planning, durable powers of attorney, trusts and insurance. For more information, contact:

AARP

601 E Street, N.W.
Washington, DC 20049
Telephone: 202.434.AARP
Website: <http://www.aarp.org>

The Administration on Aging

The Older Americans Act of 1965 (OAA) called for a broad range of services and opportunities for older Americans, especially those at risk for losing their independence. It established the Administration on Aging (AoA), an agency of the U.S. Department of Health and Human Services, as the focal point for administering aging programs. AoA works closely with its nationwide network of State Units on Aging and Area Agencies on Aging to plan, coordinate and develop services and delivery systems. Services include information and referral, outreach, case management, escort, home-delivered meals, congregate meals, day care, home repair and rehabilitation, nursing home ombudsman, legal services, employment counseling and referral, and health promotion programs. Services for caregivers include respite, counseling and education programs.

For information about local services, older persons and caregivers can contact their Area Agency on Aging. AAAs are usually listed in the telephone directory under "Aging Services" or "Senior Services" in their city or county government headings. The Eldercare Locator, a nationwide toll free hotline, provides information about assistance for older individuals anywhere in the country. Callers are asked to supply the older person's address and zip code number.

Eldercare Locator:

800.677.1116

<http://www.aoa.dhhs.gov/caregivers/default.htm>



WEBSITES

There are now hundreds of Internet sites with information on caregiving. Some are operated by non-profit membership groups and organizations. The Family Caregiver Alliance and the Alzheimer's Association (described earlier) have two exceptionally comprehensive and informative sites. Other national organizations have sites that focus on specific illnesses or disabilities. These include the National Parkinson Foundation (<http://www.parkinson.org>) and the National Institute of Neurological Disorders and Stroke (<http://www.ninds.nih.gov>).

Commercial sites that focus on caregiving are operated by businesses such as homecare agencies. While these commercial sites typically have products or services for sale, many are operated by professionals in the field of aging and offer valuable free information, advice and support.

A good starting point for finding online resources for caregivers are the web pages of state, area and local government and service agencies. Several good sites are listed below:

Governmental and Non-Profit websites

National Aging Information Resource Center

Resources for Caregivers

<http://www.aoa.gov/NAIC/Notes/caregiverresource.html>

This site, operated by the Administration on Aging (AoA), includes information on AoA-funded projects, other federal government sites, articles, national caregiver organizations and other Internet sites.

Caregiver Resources

Washington University-St. Louis

<http://www.biostat.wustl.edu/ALZHEIMER/submit/caregive.html>

This site describes and has links to over 100 sites for caregivers. Resources provided on these sites range from videos on Alzheimer's disease for teenagers, to personal accounts and tips from other caregivers, to information on insurance and public benefits programs.

Commercial Sites

Today's Caregiver Magazine

<http://www.caregiver.com/>

An online magazine offering advice and feature articles, discussion forums and other resources.

Alzheimer List and Alzheimer Digest

<http://www.adrc.wustl.edu/ALZHEIMER/frame.html>

This site includes an email discussion group for patients, professional and family caregivers, researchers, public policy makers, students and anyone with an interest in Alzheimer's disease or related dementing disorders.

CaregiverZone.com

<http://www.caregiverzone.com>

This site, operated by experts in the field of aging, offers a newsletter, personal stories and a database of services.

CareGuide.com

<http://www.careguide.com>

Operated by a care management company, this site offers professionally moderated online support groups, instruction in how caregivers can assess their need for assistance, and information on financial and legal issues.

CaregiversCount.com

<http://www.CaregiversCount.com>

This site was designed to inform family caregivers about activities and developments in Washington, D.C., and to empower them to effectively advocate for or against positions or programs.

TRAINING CURRICULA, REPORTS AND ADDITIONAL READING

A Model Intervention for Elder Abuse and Dementia.

This curriculum was designed for workers in the field of adult protective services and Alzheimer's Association personnel in the Cleveland, Ohio area. It contains referral protocols to improve communication and promote cooperation among organizations that provide services to caregivers and those that provide protective services. It also contains assessment guides for use by Alzheimer's Association employees to assist them identify individuals and families at risk for abuse and screening tools to help APS workers identify functional limitations, cognitive impairment, depression and problem behavior. For more information, contact:

**Office of Geriatric
Medicine/Gerontology
Northeastern Ohio Universities
College of Medicine**

P.O. Box 95, Rootstown, OH 44272-0095
330.325.6359
email: brp@neucom.edu

Preventing Stress from Becoming Harmful: A Guide for Individuals Who Care for Persons with Dementia.

Also available from the Office of Geriatric Medicine/Gerontology at Northeast Ohio Universities College of Medicine (above), this handbook is a self-assessment guide to help caregivers identify their own risk of becoming abusive. It further offers suggestions for lowering the risk. The handbook is available in English and Spanish versions.



A House Divided — Caregiver Stress and Abuse of the Elderly.

Video directed by Lyn Wright, National Film Board of Canada. 1988. Available on 16mm film; 3/4", VHS, and BETA video cassettes. The U.S. distributor is Filmmakers Library. For more information, contact:

Filmmakers Library

124 East 40th Street
New York, NY 10016
<http://www.filmmakers.com>
Phone: 212.808.4980
e-mail: info@filmmakers.com

Caregiving: Helping the Elderly with Activity Limitations.

This profile is part of a series, Challenges for the 21st Century: Chronic and Disabling Conditions, produced by the National Academy on an Aging Society, a policy institute of The Gerontological Society of America.

Copies can be ordered by calling:
202.408.3375

The publication can also be downloaded from the National Academy on an Aging Society's web site at:
www.agingsociety.org/Caregiving.pdf.

Agitation in Older Persons with Dementia:

A Guide for Families and Caregivers. This guide, produced in 1998 by David A. Kahn and his colleagues, is part of the Expert Consensus Guideline Series. It was designed to provide guidance in caring for people with Alzheimer's disease who become agitated. Simple techniques are given to identify the source of the person's agitation and how to minimize anxiety, frustration or physical discomfort that can lead to agitation. Also discussed are medications the person's doctor can prescribe and resources for families. It is available online at:

www.psychguides.com/gltreatment_of_agitation_in_dementia.html.

***Helping the Helpers: State
Supported Services for Family
Caregivers.***

Developed by AARP, this report provides policymakers and advocates with an overview of state programs that support family caregivers. It profiles programs ranging from comprehensive statewide service programs to small, innovative outreach campaigns. The report draws from two 1999 surveys: a California Family Caregiver Alliance (FCA) survey of 33 caregiver support programs in 15 states and a survey by the National Association of State Units on Aging (NASUA) of innovative caregiver support programs in 10 other states. Copies can be obtained by contacting AARP's :

Public Policy Institute

601 E Street, N.W.
Washington, D.C. 20049
(ask for publication ID: 2000-7)

It is also available on AARP's website at:
[http://research.aarp.org/health/
2000_07_help.pdf](http://research.aarp.org/health/2000_07_help.pdf)

ADDITIONAL PUBLICATIONS ON ELDER ABUSE

If you find this publication useful, you may want to order other publications produced by the Institute on Aging for the National Center on Elder Abuse. Available publications include:

- ***Mental Health Issues in Elder Abuse*** (2000)
- ***Helping Hands: The Role of Adult Protective Services in Preventing Elder Abuse and Neglect*** (2000)
- ***Forgotten Victims of Elder Financial Crime and Abuse: A Report and Recommendations*** (1999)
- ***Victims' Rights and Services: Assisting Elderly Crime Victims*** (1999)
- ***Prosecution and Protection: Understanding the Criminal Justice System's Role in Preventing Elder Abuse*** (1998) Co-authored by Candace Heisler, JD.
- ***Communities Uniting: Volunteers in Elder Abuse*** (1997)
- ***Financial Abuse of the Elderly*** (1996)
- ***Older Battered Women: Integrating Aging and Domestic Violence Services*** (1996)
- ***To Reach Beyond Our Grasp: A Community Outreach Guide for Professionals in the Field of Elder Abuse Prevention*** (1995)
- ***Building Partnerships: A Guide to Developing Coalitions, Interagency Agreements, and Teams in the Field of Elder Abuse*** (1995)

Also available from the Institute on Aging:

- ***Serving the Older Battered Woman, a Conference Planning Guide*** (1996, \$30)
- ***Domestic Violence and the Elderly: A Cross Training Curriculum*** (1998, \$20)
- ***Video: When Help Was There: Four Stories of Elder Abuse*** (2000, \$79.99)

- ◆ Each book is available for \$15 (California residents, please add 8.5% sales tax)
- ◆ Bulk rates are available
- ◆ Make checks payable to:

Institute on Aging

(Federal tax Identification
Number 94-2978977)

Attention: Elder Abuse Prevention Program
3330 Geary Boulevard
San Francisco, CA 94118

- ◆ Phone: 415.447.1989 Ext. 519
- ◆ E-mail: ElderAbusePrevention@ioaging.org