

MANAGING THE STRESS OF CAREGIVING: A GUIDE

Managing the Stress of Caregiving: A Guide for Consumers and Financial Advisors

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Abstract

The aging US population increases the need for caregiving for this expanding demographic. People with or without long-term care insurance will still need care from professional caregivers or family. Caregiving from family members, while having some rewards, may cause stress and depression that leads to overall poorer quality of life for caregivers. The paper starts with a focus on defining and observing caregiver stress, as well as its symptoms and effects. The paper transitions to a guide for consumers and financial advisors, giving recommendations and resources beneficial for assisting consumers in the caregiver role and in need of help.

Introduction

Although not formally recognized by the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM), caregiver syndrome, also referred to as "caregiver stress," or "caregiver burden," can cause both physical and mental health afflictions. Often, caregivers are so intent on caring for the individual needing care that they ignore or neglect their own needs.

Many caregivers are found caring for individuals with Alzheimer's or dementia. Alzheimer's and dementia are different. Alzheimer's is a disease defined as abnormal changes in the brain that affect memory, decision making and reasoning. Dementia, while not a disease, is a term associated with cognitive decline. Dementia may have the same symptoms as Alzheimer's disease, but the causes of dementia may be entirely different, such as suffering severe head injury or stroke, Parkinson's Disease, and others which may lead to chronic disorder of mental functioning.

Although labeled above as "caregiver syndrome," the condition can be broken down into two categories called "caregiver burden" and "caregiver stress" (Quadagno, 2014). "Caregiver burden" is defined as the actual management involved in the tasks, while "caregiver stress" is the strain or emotional toll caregiving has on an individual. For brevity, we will use the term caregiver stress to include caregiver burden or caregiver syndrome for the remainder of the paper.

The main symptom of caregiver stress is depression. Other symptoms include fatigue, insomnia, and anger. The paper will act as a "reference guide" for advisors to individuals giving care or who see the role as inevitable. Advisors can help individuals identify causes, as well as provide potential ways to cope with the stress, while not necessarily eliminating it.

While caregivers can be family, friends, or professionals, this paper will focus on the impact of caregiving stress on families – particularly spouses and children of those individuals needing care. Those are the family members who are most likely to provide care to individuals (Quadagno, 2014).

ADLs and IADLs

Generally, the need for care arises when an individual is unable to perform activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs). ADLs consist of being able to feed oneself (eating), bathing, getting dressed, transferring from a bed to chair, using the toilet and continence. ADLs are generally considered to be of more essential, basic living activities than their IADL counterparts. IADLs are activities such as paying bills, running errands, house chores and taking medication.

The difference between ADLs and IADLs is a crucial factor for consumers and their advisors to understand, as together, they are the skills needed to live independently (Caring.com). However, differences between ADLs and IADLs may determine which policy an advisor recommends and which policy a consumer should choose.

IADLs are generally more complex, requiring more cognitive skill than ADLs, and thus, disabilities represent less-severe dysfunction than ADLs (Wiener, Hanley, Clark & Van Nostrand, 1990). Thus, individuals often lose the ability to perform IADLs before losing the ability to perform ADLs. Paradoxically, most tax-qualified long-term care insurance policies do not have an individual's loss of ability to perform IADLs as policy "triggers".

Most tax-qualified long-term care insurance policies will generally trigger (start payment of benefits) if a covered individual suffers severe cognitive impairment (Alzheimer's or

dementia) or is unable to perform the duties of two of six ADLs for a period expected to last for a period of 90 days, (certified by a licensed health-care professional). However, individuals and advisors can seek long-term care insurance policies that provide more flexibility covering both ADLs and IADLs (Bergstrom, 1999). Specific recommendations are provided later in the guide.

While the above description attempts to “quantify” long-term care, there is more to long-term care than acronyms. One study by the National Alliance for Caregiving participants explained the need for a better language or vocabulary when talking about caregiving. Participants described terms such as “informal caregiver,” which makes their role in care seem small or insignificant and explained that using acronyms such as ADLs and IADLs diminished the true amount of work and difficulty in performing some of those tasks.

Caregiving can be done in the home, nursing home, assisted living facility, adult day care or a combination thereof. Regardless of where the care takes place, families rarely give up their duties of caregiving either at home or in the nursing home (Quadagno, 2014).

While long-term care insurance can relieve some of the physical and financial stress of caregiving, it may not eliminate it. Regardless of coverage, most caregivers will experience physical, mental and financial stress. It’s important to provide caregivers with knowledge of the caregiving stress and how it applies to them. Then potential resources and solutions can be provided by the advisor to help consumers cope with, and potentially alleviate, the stress of caring for another individual.

Literature Review

In 2009 over 65 million people in the US served as unpaid caregivers, 66% of whom are female and caring for an individual for over 4.6 years (Caregiving, 2009). The reasons

for the necessity of care included the physical frailty of old age (12%) and Alzheimer's or dementia (10%) (Caregiving, 2009). In other words, roughly 6.5 million caregivers are caring for someone with Alzheimer's or dementia.

Most caregiving is done by family members with the majority of care being provided by children, followed by spouses (Quadagno, 2014). One study showed that caregivers of individuals with less severe needs or absence of dementia were younger and often employed full time. This added to the stress of their lives and the stress of care (Cohen et al., 2014).

Most caregiving is being done by women with the majority being daughters and wives (Quadagno, 2014). Another study found that 66% of caregivers are female providing care for an average of 4.6 years (Caregiving, 2009). For daughters in particular, this can add to the caregiving stress, as they don't give up their other responsibilities such as working, raising a family and other obligations.

While children giving care experience stress, spouses are much more likely to have higher amounts of stress. The caregivers are around the spouse needing care almost all the time, and this situation means they are less likely to get a break from the constant care. One study by AARP found that 60 percent of caregivers caring for individuals with challenging behaviors felt they didn't have a choice in providing care and felt more stressed because of that pressure.

Caregiver stress can lead to a number of different ailments, afflictions and health issues for the caregivers. Several studies have shown that caregivers can suffer from exhaustion, poor immune systems (Bedard et al., 2000), depression, and high blood pressure (Coe & Van Houtven, 2009). More serious conditions may arise, such as heart disease, stroke, and increased mortality – particularly for those providing care for a disabled spouse (Quadagno, 2014).

Additionally, Shulz & Sherwood (2008) found that caregivers helping family members with dementia found a higher degree of stress and challenge as opposed to those not giving dementia care. People suffering from dementia require more supervision and are less likely to understand or be grateful for the care they are being given. Another study by AARP found that nearly half of the survey participants felt higher levels of stress when performing medical or nursing caregiving as opposed other respondents not giving that type of care.

Caregiver stress has also been linked to increased levels of the stress hormone cortisol. Added levels of stress have been related to the length of the duration of caregiving, behavioral problems of the recipient, relationship of the caregiver (spouses more affected) and gender (Shulz & Sherwood, 2008). Some caregiving duties are more difficult than others. In the aforementioned six ADLs, continence and transferring can be some of the most difficult and frustrating tasks. For example, a small wife caring for her larger husband can experience tremendous physical and mental strain. Urinary and fecal incontinence are leading causes for nursing home placement (Scott, 2014).

In addition to the physical and mental stress placed on caregivers, there is also the financial stress placed on those providing care. Lack of or reallocation of finances in order to pay for caregiving has resulted in lost wages (Wakabayashi & Donato, 2006). This can have a multiplicative impact, particularly on the caregiving daughter as she may have to leave work or reduce hours thus lowering her income. It may also impact her later in life as she is statistically likely to live longer than her spouse, but has not saved much for her own care or retirement. Some of this stress is potentially relieved, but not eliminated, through employers allowing flexible work schedules and the impact of the Family and Medical Leave Act (Quadagno, 2014).

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Financially, the impact of caregiving is onerous. According to the MetLife Study of Caregiving Costs to Working Caregivers the total estimated amount of lost wages to caregivers is \$3 trillion. Caregiving males can expect to lose a total of \$303,880 in lost wages due to caregiving, while, not surprisingly, females can expect to lose more – approximately \$324,044 in lost wages from caregiving. This impacts not only wages but long-term plans such as the ability to save for retirement.

The financial impact of care not only applies to the recipient needing or using funds to pay for care, but it can also impact the sibling caregiver after the parent(s) have passed away. Filial laws apply in 29 states in the US, requiring children to pay any unpaid nursing home bills left by parents who used those facilities, with two states (Pennsylvania and South Dakota) enforcing the laws in order to recoup money owed by former nursing home residents (Pearson, 2013).

The average annual cost for nursing home is care is approximately \$80,000 for a semi-private room and just over \$91,000 for a private room (Genworth). Certain states or geographical areas may have higher or lower costs. For example, Texas averages just over \$51,000 while Alaska averages just over \$281,000 for a semi-private room (Genworth). Financial advisors who recommend long-term care insurance are on the preventative side of transferring the financial risk of caregiving that long-term care insurance provides. Those advisors can also have information available to educate consumers on the resources available to family caregivers. In other words, instead of focusing on what should have been done, advisors can recognize when a client is stressed and help consumers recognize and focus on how to manage that stress going forward.

Financial advisors may find this information useful for a number of reasons. By the year 2030, adults age 65 and over will account for 20% of the population in the US (CDC). These individuals along with their children will have long-term care questions and needs that advisors can help with, directing them on possible products, as well as caregiving solutions to the stress noted above. Currently two out of three older Americans suffer from chronic illnesses such as cancer, heart disease, stroke, Alzheimer's, and diabetes (CDC). This means that potentially 66% of the population may be in need of care.

The need for solutions to the caregiver stress will not go away. The goal of this paper is to help financial advisors identify potential caregivers and guide caregivers on solutions to the caregiving stress. While not an attempt for advisors to eliminate the caregiver stress entirely, advisors can certainly use this paper as a resource to aid consumers who need help, while also *indirectly* fulfilling their professional responsibility and adding value to the overall client/advisor relationship.

The Guide

While certainly not exhaustive and conclusive, this section intends to outline resources and solutions that financial advisors may find beneficial for caregiving consumers. The solutions are designed to help with the need for coping with caregiver stress. These solutions may provide some respite for caregivers looking for a way to alleviate the stress of caregiving without feeling guilty that they may be alienating the care recipient. Unfortunately, there is no single source to get access to resources and help. However, the advisor can provide a starting point and use the following resources in this section to benefit caregivers.

Before Care is Needed

How Advisors Can Identify Caregivers

Individuals who see themselves being placed in a caregiver role may need to look for resources before the care is needed. However, caregivers may not know where to find beneficial information. Financial advisors are in an excellent position to identify consumers with caregiving needs. As part of the initial fact-finding process, advisors may inquire about the consumers' long-term care questions and concerns, and may offer information regarding long-term care and potential stress it can place on caregivers.

Information may include reprints of articles on caregiving stress or brochures that will help the client identify whether they are experiencing, or may experience, similar stress in the future. Finally, the advisor can provide a list of resources available to assist the caregiver in managing their care duties. The list may include the following:

Long-term Care Insurance

Long-term care insurance can be an invaluable tool to help caregivers and recipients with the stress of care as well as potentially protecting the assets of the recipient. Tax-qualified long-term care insurance is generally defined as insurance that helps pay the costs of care associated with an individual who is expected to be unable to perform at least two of the six ADLs for a period of 90 days, or has severe cognitive impairment as determined by a licensed health care professional. To use its benefits, long-term care insurance must be in place before the impairments manifest.

When evaluating policy options, advisors and consumers must be cognizant of what a policy will and will not cover. An advisor or consumer may be keen on the tax benefits of a tax-

qualified long-term care policy, but may be unaware that the policy may restrict losing the ability to perform IADLs as a policy trigger.

For example, a non-qualified long-term care policy may not have the requirement of certification by a health care professional of the insured being unable to perform the two of the six ADLs for a period of 90 days. Additionally, a non-qualified policy may be more comprehensive in that policy triggers can be both ADLs and IADLs. However, non-qualified policy premiums are not tax-deductible, and may be more expensive due to being less restrictive.

Families may find it beneficial to discuss long-term care insurance as an option to help with care. Families may also discuss potential ways to fund premiums with some policyholders funding the policy personally or siblings helping fund or purchasing policies on parents. One of the benefits of long-term care insurance is that it will pay for custodial care while Medicare does not. Qualified long-term care insurance premiums may also be itemized deductions, subject to an income floor (IRS Pub. 502).

Legal Planning Documents

Consumers may also consider talking to an estate planning attorney or elder care attorney. These professionals can establish legal documents in the event that the family member becomes incapacitated or incompetent. Legal documents, such as powers of attorney, living wills, and health care proxies can help the caregiver and care recipient make difficult decisions for the future. This may help caregivers and family members avoid potential arguments and can help assist medical staff.

The following is a list of legal planning documents and their benefit to caregivers and recipients (NIA, 2013):

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- Will – identifies how a person’s assets will be divided and distributed at death and may identify guardians for minors, trusts (testamentary), and burial wishes.
- Living will – identifies the wishes of a person’s medical treatment toward the end of their life. Living wills help establish the extent of medical care a person wants and the choice to die with dignity.
- Durable power of attorney for health care (health care proxy) – allows the person with the power (called the agent or proxy) to make decisions when the person receiving care cannot, as may be the case with Alzheimer’s or dementia. Such decisions may be continuation of life support, removal from a hospital, and organ donation.
- Do not resuscitate order – tells medical staff not to initiate CPR or other lifesaving measures if the heart stops beating or a person stops breathing.
- Durable power of attorney for finances – financial decisions can be made on the recipient’s behalf.
- Beneficiary designations – it will be important for the client to make sure their beneficiaries are updated and correct on IRAs, life insurance policies, and employer sponsored retirement plans (401(k), etc.).

If an individual doesn’t have one or any of the above documents, their wishes may not be fulfilled and there is the risk that caregiver stress can increase. For example, dying without a will (intestate) leaves decisions on how assets are distributed up to the laws of the state in which the individual resided. If there isn’t a health care power of attorney or living will established, family members will have to decide (and may argue about) what the person would have wanted.

Individuals without family or if family cannot come to a decision may have a court establish a guardian to make decision on the individual's behalf (Tufts).

From a practice management standpoint, this is an excellent opportunity for the advisor to recommend and or provide long-term care planning for the consumer and their spouse or partner. Consumers in the caregiver role will likely be more receptive to planning recommendations and will likely find value to the advice and recommendations the advisor provides.

Once Care Starts

Once caregiving has started and the caregiver is feeling stress, a starting point can be to simply admit that the caregiver is stressed and needs help. Advisors can discover consumers who may be undergoing the stress of caregiving by asking questions throughout the initial interview or subsequent reviews. Once the need for help has been established, the caregiver and advisor can look at several areas to see what methods, organizations, and people are available to help.

Advisors may need to refer consumers to other professionals more experienced and who specialize in this type of planning. The advisor and client may need to team with elder care attorneys, counselors, or specialists in long-term care financing. In this situation, the advisor acts as the "general contractor," giving the client direction to the professional most suitable to help.

How Caregivers Can Ask for Help

Caregivers often find themselves confused on where to start and what action they need to take to help provide care. Participants in one roundtable discussion found that there was a need for coaches to help them navigate the technology available to assist with caregiving (Catalizing). Caregivers may want to sit down with other family members to discuss the situation and

formulate a care plan for the recipient. Talking with family and formulating a plan may also be beneficial when symptoms of diseases such as Alzheimer's and dementia first appear. Plans can be devised as to who will be the primary caregiver, who will help with finances, and what the family members' roles will be (Powell, 2014).

Asking family and friends to help with certain tasks may also be beneficial. While willing and happy to help, the caregiver must realize that it's up to the caregiver to ask for help and not expect family or friends to ask the caregiver (Caregiver's Handbook). Visits and assistance from family and friends can help with loneliness, caregiving, and emotional stresses involved with providing care. The main point is for the caregiver to ask for help.

Caregivers must realize that asking for help is not a sign of weakness or a sign of selfishness. Caregiving is very demanding, and caregivers often feel that asking for help is bothering the person they're asking, when in fact a person may want to help but doesn't know how. Mayo Clinic and Net of Care give ways caregivers can ask for help:

- Identify specific areas where the caregiver needs help.
- Ask if there's a specific area where others would like to help.
- Identify areas where the caregiver thinks others can help.
- Be direct when asking (avoid beating around the bush).
- Match the helper's abilities to tasks needed to be done.

Caregivers must also be prepared if someone they ask says no. This doesn't mean the person they asked doesn't care. It may mean that they don't have the time, are uncomfortable helping, or have other personal priorities they need to deal with first.

In addition to asking for help, caregivers can look to professional geriatric care managers. Professional geriatric care managers are essentially coaches, and are qualified to assist caregivers with planning; coaching; identifying financial decisions to be made; and managing medical needs, housing, and safety issues. (Caremanager.org). Financial advisors can work with professional geriatric care managers and may be able to refer consumers to their local care manager when consumers are seeking help or looking for a place to start.

Resources to Finance Care – an Inventory

Caregivers and family may consider searching for resources already in place that can help with the financial stress of caring for an individual. One study found in a telephone survey, that caregivers spend approximately \$5,531 annually in caring for an individual, while long distance caregivers spend \$8,728 (Evercare). The same survey also recorded the diaries of caregivers and those respondents reported paying \$14,832 annually living with the recipient versus \$14,064 for long distance caregivers (Evercare).

As part of the initial and ongoing fact-finding process, advisors can help identify potential financial resources that caregivers and family may use to help pay for care. These resources may include in-force long-term care policies and in-force life insurance policies with cash value or long-term care riders. Additionally, more resources may include retirement plans such as IRAs, employer sponsored plans, and non-qualified investment accounts. Advisors can help caregivers take inventory of what assets are available and may find it beneficial to understand where such documents would reside (file cabinet, safe deposit box, an attorney's office). There's also the possibility of taking out a reverse mortgage on the home. If the need for

a reverse mortgage arises, the advisor can direct them to HUD.gov where they can research the benefits of a home equity conversion mortgage (HECM).

Respite

Respite care is when a caregiver needs a break from their caregiving duties and may hire formal or informal help to relieve the caregiver temporarily of their duties. Examples of formal care include the caregiver dropping the recipient off at an adult day care, hospital, or medical center such as a VA medical center. Informal care consists of the caregiver asking a family member or friend to sit with the recipient for a certain time while the caregiver takes a break to run errands, attend events, or take a nap. Respite care has been shown to increase quality of life for caregivers (Lawton et al., 1989).

Caregivers concerned with the costs of adult day care, respite services, or other formal care may find it helpful to communicate with the respite providers to get an understanding of the costs. Some adult day care centers may provide cost reductions on a sliding scale according to caregiver and recipient income, and Medicaid may provide assistance in some states (Alz.org).

In addition to the respite given to the caregiver, adult day care centers are more affordable than in-home care (Caregiverslibrary.org). Adult day care centers also allow the caregiver the ability to keep working, thus helping reduce, if not eliminate, the concern of lost wages during the period of caregiving. This option may also provide relief for caregivers struggling with the financial and mental stress of deciding whether or not to place their loved one in a nursing home.

Caregivers may be able to contact local colleges and universities to see if students in the field of health care or social services are looking for internships or service work in the field of

long-term care to satisfy degree requirements. This may be a way for the caregiver to get assistance for very little, if any, cost.

The following is a list (with URLs) that can assist advisors directing consumers to respite options:

- The Caregiver Action Network (also The National Family Caregivers Association) gives an excellent link to respite care for children, adults, and other family members. http://www.care.com/respite-nfca-p1087-q202887.html#utm_content=&utm_medium=partner&utm_campaign=seeker_general&utm_source=partner&utm_term=nfca&
- AARP has a section on their website dedicated to caregivers needing relief to help them develop a plan of respite care. Options include an eldercare locator to direct them to community resources and ways to develop community care co-ops and support groups. www.aarp.org/relationships/caregiving-resource-center/info-09-2010/pc_develop_a_respite_plan.html
- Caring.com provides a wonderful resource article that walks a caregiver through some of the respite care options and how to access those options. Such options include how to ask family for help, personal care assistants, adult day care, and area agencies on aging.

<https://www.caring.com/articles/respite-care>

<https://www.caring.com/local/adult-day-care>

- Advisors can direct consumers to their local Area Agency on Aging. N4A.org provides a list of agencies, state and city specific. For example, the author was

able to go to the site, click on the state, then city of residence and was taken to the website of the local agency and found a number of resources including a handbook on caregiving. <http://www.n4a.org/>

- Caregivers of veterans can take advantage of the caregiver resources offered by the Department of Veterans Affairs. In addition to the services provided for veterans, caregivers may find the VA's adult day health care centers beneficial as a way to take some personal time while the veteran engages in activities and socializing. Additional services include home based primary care and skilled home care for individuals who find it hard to travel from the home. The VA also allows up to 30 respite days per year at home or at on-site centers to allow caregivers time to relax and rejuvenate or in event of an emergency that requires the caregiver temporarily relinquish duties. <http://www.caregiver.va.gov/>

Work and Caregiving

Often caregivers are doing double duty as a caregiver and working their normal job. The impact on caregiving affects employers also. According to the Metlife Caregiving Cost Study, the employer's costs for full-time caregivers was \$33.6 billion. Caregiving has shown to have a negative effect on employee mood and happiness, while also negatively affecting the employer's bottom line (Duxbury, Higgins, & Smart, 2011). Increased stress on caregiving employees also led to increased work absences and increased spending on prescription medications (Duxbury et al., 2011). The Family and Medical Leave Act can assist a caregiver should they need to take time off to care for a family member who is ill. Under the FMLA, a covered employee may be able to take as much as 12 weeks off of work (generally without pay) to care for an individual (DOL Employee Guide). There are some restrictions, for example, the employer must be a

covered employer (generally has 50 or more employees) and the employee must have worked for the employer for at least twelve months and must have worked at least 1,250 hours.

Caregivers can communicate with their employers regarding possible flexibility of work and the potential for telecommuting, working non-traditional hours, or other arrangements that are mutually agreeable. Employers can also help by establishing plans (whether or not they're covered by the FMLA) to support caregivers (Catalyzing). In addition, many employers offer employee assistance programs to assist caregivers.

Caregivers who find that they're hesitant to ask their employers for help or are looking for a way to "break the ice" may consider caregiver coaching resources. Caregiving coaches can help caregivers by informing them of their options through work, helpful approaches to use with employers and family, as well as ways to manage the daily chores of caregiving. Coaching may also be a beneficial way for the caregiver to learn to take time for themselves in a positive way, without feeling guilty that they may be ignoring the loved one receiving care.

Caregiver Wellness

Caregivers need to make time for their own care and health. That is, caregivers are often so engaged in caring for the recipient that they neglect their own health and well-being. Financial advisors can be helpful to caregivers who would benefit from health and wellness suggestions. Advisors can direct caregivers to resources on wellness. Specifically, Caring.com has a section on caregiver wellness (<https://www.caring.com/caregiver-wellness>) that has links regarding healthy food choices, getting proper sleep, how to manage caregiver burnout, and a blog area that caregivers can go to take a break and relax while reading and enjoying non-caregiver reading and entertainment.

Caregivers can also improve their well-being by taking advantage of respite resources available (see above). Having time to focus on themselves and things they enjoy can relieve some of the stress involved with caregiving. This can reduce the psychological health effects of increased depressive symptoms that many caregivers face (Sheets & Mahoney-Gleason, 2010).

Conclusion

Caregivers can be considered individuals with long-term care needs as well. While not suffering from the same diseases and afflictions as their care recipients, caregivers do suffer from mental, physical and social stress.

By using the resources provided in this paper, consumers and financial advisors can have resources available to assist caregivers in finding solutions that won't eliminate, but may certainly reduce the toll caregiver stress takes on a caregiver. By focusing on what can be done moving forward, advisors can help consumers effectively cope with the stress and turn a daunting task into a manageable one.

There has been focus on how financial advisors can assist consumers with asset protection using long-term care insurance. Asset protection aside, further research may warrant studying the impact stress has on the longevity of caregivers and recipients. This may assist financial advisors with helping consumers protect their well-being through quality of life counseling and a product independent financial planning approach.

References

Activities of Daily Living: What are ADLs and IADLs? Retrieved from

<https://www.caring.com/articles/activities-of-daily-living-what-are-adls-and-iadls>

Adler, R. & Mehta, R. (2014). Catalyzing Technology to Support Family Caregiving. Retrieved

from http://www.caregiving.org/wp-content/uploads/2010/01/Catalyzing-Technology-to-Support-Family-Caregiving_FINAL.pdf

Alzheimer's and Dementia Caregiver Center. Retrieved from

<http://www.alz.org/care/alzheimers-dementia-adult-day-centers.asp>

Alzheimer's Caregiving: How to Ask for Help. Mayo Clinic. Retrieved from

<http://www.mayoclinic.org/healthy-living/caregivers/in-depth/alzheimers-caregiver/art-20045847>

Alzheimer's Disease and Caregiving. Retrieved from

<https://caregiver.org/alzheimers-disease-caregiving>

Bedard, M., Pedlar, D., Martin, N., Malott, O., & Stones, M. (2000). Burden in Caregivers of Cognitively Impaired Older Adults Living in the Community: Methodological Issues and Determinants. *International Psychogeriatrics*, 12, 307-32.

Bergstrom, R. (1999). Buyer Beware: Tax-qualified long-term care insurance may not be a client's best bet. *Journal of Accountancy*. Retrieved from

<https://www.journalofaccountancy.com/issues/1999/aug/bergs.html>

Caregiving in the US 2009. National Alliance for Caregiving in Collaboration with AARP.

MANAGING THE STRESS OF CAREGIVING: A GUIDE

Retrieved from

http://www.caregiving.org/pdf/research/Caregiving_in_the_US_2009_full_report.pdf

Caregiving Resource Center. Retrieved from

<http://www.aarp.org/home-family/caregiving/?intcmp=HP-LN-CRGVNG-CRC>

Chronic Diseases and Health Promotion. Retrieved from

<http://www.cdc.gov/chronicdisease/overview/>

Coe, N. & Van Houtven, C. (2009). Caring for Mom and Neglecting Yourself? The Health Effects of Caring for an Elderly Parent. *Health Economics*, 18(9), 991-1010.

Cohen, L., Zimmerman, S., Reed, D., Sloane, P., Beeber, A., Washington, T., Cagle, J., & Gwyther, L.. (2014). Dementia in Relation to Family Caregiver Involvement and Burden in Long Term Care. *Journal of Applied Gerontology*, 33(5), 522-540.

Department of Veterans Affairs. VA Caregiver Support. Retrieved from

<http://www.caregiver.va.gov/>

Duxbury, L., Higgins, C., & Smart, R. (2011). Elder Care and the Impact of Caregiver Strain on the Health of Employed Caregivers. *Work*, 40(1), 29-40.

Genworth Cost of Care Survey. Retrieved from

https://www.genworth.com/dam/Americas/US/PDFs/Consumer/corporate/130568_04011_5_gnw.pdf

Health Care Proxy and Decision Making. Tufts University. Retrieved from

<https://www.tuftsmedicalcenter.org/patient-care-services/Patient-Rights/Health-Care-Proxy-Medical-Decision-Making.aspx>

Home Equity Conversion Mortgages for Seniors. Retrieved from

http://portal.hud.gov/hudportal/HUD?src=/program_offices/housing/sfh/hecm/hecmhome

Lawton, M., Brodey, E., & Saperstein, A. (1989). A Controlled Study of Respite Service for Caregivers of Alzheimer's Patients. [Abstract] *The Gerontologist*, 29, 8-16.

Legal and Financial Planning for People with Alzheimer's Disease Fact Sheet. National Institute on Aging. Retrieved from

http://www.nia.nih.gov/sites/default/files/legal_and_financial_planning-final_10-14-13.pdf

Long-term Care. IRS Publication 502. Retrieved from

http://www.irs.gov/publications/p502/ar02.html#en_US_2013_publink1000178974

National Association of Geriatric Care Managers. What You Need to Know. Retrieved from <http://www.caremanager.org/why-care-management/what-you-should-know/>

Net of Care. How to Ask for Help. Retrieved from

http://www.netofcare.org/content/getting_started/asking.asp

Pearson, K. (2013). Filial Support Laws in the Modern Era: Domestic and International Comparison of Enforcement Practices for Laws Requiring Adult Children to Support Indigent Parents. Retrieved from

http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2079753

Powell, R. (2014). Financial Planning for Dementia. USA Today online. Retrieved

from <http://www.usatoday.com/story/money/columnist/powell/2014/10/11/retirement-dementia-alzheimers-finances/17035415/>

Quadagno, J. (2014). Aging and the Life Course: An Introduction to Social Gerontology. 6th

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Edition. The McGraw-Hill Companies, New York.

Reinhard, S. & Samis, S. (2014). Family Caregivers Providing Complex Chronic Care to People with Cognitive and Behavioral Health Conditions. AARP Public Policy Institute.

Retrieved from

http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/2014/family-caregivers-cognitive-behavioral-AARP-ppi-health.pdf

Schulz, R. & Sherwood, P. (2008). Physical and mental Effects of Family Caregiving. American Journal of Nursing, 108(9).

Scott, P. (2011, Jan. 29). 5 Biggest Issues That Sabotage Family Caregivers. [Web log comment]. Retrieved from <http://www.caring.com/articles/caregiver-issues>

Sheets, C., & Mahoney-Gleason, H. (2010). Caregiver Support in the Veterans Health Administration: Caring for Those Who Care. Journal of the American Society on Aging, 34(2).

The Caregiver's Handbook. Retrieved from

<http://www.acsu.buffalo.edu/~drstall/hndbk0.html>

The MetLife Caregiving Cost Study: Productivity Losses to US Business. Retrieved from <http://www.caregiving.org/data/Caregiver%20Cost%20Study.pdf>

The MetLife Study of Caregiving Costs to Caregivers. Retrieved from

<http://www.caregiving.org/wp-content/uploads/2011/06/mmi-caregiving-costs-working-caregivers.pdf>

US Department of Labor Wage and Hour Division. Need Time? The Employee's Guide to the Family and Medical Leave Act. Retrieved from

<http://www.dol.gov/whd/fmla/employeeeguide.pdf>

MANAGING THE STRESS OF CAREGIVING: A GUIDE

Wakabayashi, C., & Donato, K. (2005). The Consequences of Caregiving: Effects on Women's Employment and Earnings. *Population Research and Policy Review*, 24, 258-274.

What is Adult Day Care? National Caregivers Library. Retrieved from

<http://www.caregiverslibrary.org/caregivers-resources/grp-caring-for-yourself/hsgroup-support-systems/what-is-adult-day-care-article.aspx>

Wiener, J., Hanley, R., Clark, R., & Van Nostrand, J. (1990). Measuring the Activities of Daily Living: Comparisons Across National Surveys. Retrieved from

<https://aspe.hhs.gov/system/files/pdf/74346/meacmpes.pdf>