

JAMA. Author manuscript; available in PMC 2013 November 04

Published in final edited form as:

JAMA. 2011 August 17; 306(7): . doi:10.1001/jama.2011.1163.

# Living with an Aging Parent: "it was a beautiful invitation"

Christine Ritchie, MD, MSPH<sup>1,2</sup>, David Roth, PhD<sup>1,3</sup>, and Richard Allman, MD<sup>1,2</sup>

<sup>1</sup>Birmingham-Atlanta Geriatrics Research, Education and Clinical Center, Department of Veterans Affairs Medical Center, Birmingham, AL

<sup>2</sup>Division of Gerontology, Geriatrics and Palliative Care, Department of Medicine, School of Medicine, University of Alabama at Birmingham, Birmingham, Alabama

<sup>3</sup>Department of Biostatistics, School of Public Health, University of Alabama at Birmingham, Birmingham, Alabama

## **Abstract**

In the United States and globally, increasing numbers of older parents are living with their adult children. The decision for older parents and their adult children to live together requires careful thought and planning. Both the older adult's and adult child's physicians should be consulted in this process. Over a third of caregivers state that when they need information about this transition, they turn to their doctor or other health care provider. In this edition of the "Care of the Aging Patient" series, we review the prevalence and epidemiology of adult children caring for a parent in their home, and describe a framework for clinicians to guide their patients through this transition. We describe the physician's ongoing role in caring for and advising both the older parent and the adult children during common stages of multigenerational living: before the move, during coresidency and subsequent care transitions.

## The Family's Story

Mr. and Mrs. M lived in the southeast until 2006 when, at the ages of 89 and 86 years, they moved across the country to live with their daughter, her husband, and their teenage children. Until the move, they lived without assistance in their own home. Mr. M, worked as a mechanical engineer, retiring at age 62. For 15 years, Mr. and Mrs. M spent summers with their daughter and her family, caring for the children while their parents worked; by 2002, however, flying for these visits became "too much."

Mrs. M had been well except for acute poliomyelitis in 1954, which left her with a weak left leg and left foot drop, and rectal cancer in 1996 treated with surgery and radiation. Mr. M had diabetes mellitus, diagnosed in the 1990s and treated with metformin1000 mg BID and glimepiride 4 mg BID; he had no end-organ complications. In 1995, Mr. M's daughter noted that Mr. M demonstrated no interest in using a map, a previously engaging activity. In 2004, Mr. M became lost while driving alone to a store and his wife assumed all driving. At this point, Mr. M and his wife shopped and handled money together and he dressed, bathed, and performed other activities of daily living (ADLs) without assistance. In 2005, Mr. M was evaluated in a memory disorders clinic and diagnosed with mild cognitive impairment. His mini-mental state examination score was 26/30, geriatric depression score 2/15, and neuropsychological testing showed impairment in executive function, learning, and memory. An MRI of the head showed moderate atrophy; laboratory tests were unremarkable. The

clinician recommended a driving evaluation, caregiver support group, and a review of legal and health care planning documents. In 2005, Mrs. M asked her daughter to help them find a condominium or senior housing. On the visit during which the selection of a facility was to have been made, Mrs. M and her daughter discussed her parents living with her. Mrs. M responded in tears that this was exactly what she most wanted. Mr. and Mrs. M moved to their daughter's home in 2006.

For the first year and a half, Mr. and Mrs. M lived on the second floor of their daughter's house, sharing meals with the family, and driving daily to attend church and shop. In 2007, Mr. M wandered from the house a few times. Mrs. M had increasing difficulty climbing stairs. Her daughter hired domestic help to be available 2–4 hours daily. In 2008, a renovation of the ground floor created an efficiency apartment for Mr. and Mrs. M. They continued to attend church and shop daily, prepared simple meals, and ate in their apartment.

Over the next 2 years, Mr. M's behavior became more troublesome to his wife, and Mrs. M had increasing difficulty walking. Mr. M rarely made sense when talking, sometimes confused his wife for his mother, "refused" to do chores his wife thought he should be capable of, slept more than she thought he should during the day, and sometimes refused to get out of bed. To get him to cooperate, she would repeat requests, yell, and sometimes tell him he would have to go to a "home." He would glare at her, and once aggressively grabbed her, injuring her wrist.

By 2009, Mr. M's walking slowed and he stopped walking outside the house. He could not shave or bathe without help. Beginning in 2010, Mr. M began to wear absorbent underwear, and he needed assistance cutting up food. His daughter hired a care provider to take Mr. M out for a walk and bathe and shave him twice a week. Although Mrs. M objected to the cost (roughly \$100/week), she began to look forward to the help. She continued to do her laundry; her daughter shopped for food and created "left-overs" for most meals. They saw their physician twice a year.

By Thanksgiving of 2010, Mr. M required assistance with all ADLs, including spoon-feeding, and assistance getting out of a bed or chair and walking; Mrs. M could not provide this assistance around the clock and a paid attendant provided care for Mr. M 4 hours daily, 5 days/week. Mrs. M received assistance with household chores, cooking meals, and finances, but could no longer drive to church. The family began to explore congregate living facilities that could accommodate both spouses, with meals and care for Mr. M. Mrs. M chose the only one that offered daily religious services. Accommodation and care for both would cost about \$8000/month and for Mrs. M alone, about \$2500/month. This and other expenses would likely consume their life savings in 3–4 years. By Christmas the move had taken place.

Mrs. M, her daughter, son-in-law, and Dr V, the physician who cares for both Mr. and Mrs. M, were interviewed by a Care of the Aging Patient editor in July 2009.

# The family's needs in perspective

**Mrs.** M: [recollecting the decision to move] When my daughter said, "Mom, would you and dad consider coming?" I thought that was the most beautiful invitation and the answer to my prayer...My husband was agreeable and we came.

A transition from an older adult's home to that of their adult child's requires careful planning and benefits greatly from the thoughtful involvement of both the older adult's and adult child's physicians. Over a third of caregivers state that when they need information about this transition, they turn to their doctor or other health care provider. We review the

prevalence and epidemiology of adult children caring for a parent in their home, and describe a framework for clinicians to guide their patients in the decision to co-reside through a living arrangement checklist. We describe the physician's ongoing role in caring for and advising both the older parent and the adult-caregiving children in each of the 3 common stages of multigenerational living: before the move, during co-residency and subsequent care transitions.

### **Methods**

We conducted separate literature reviews on the following topics: (1) adult child caregivers, (2) geriatric caregiver interventions, (3) caregivers and systematic reviews, (4) caregivers and respite care, (5) caregivers and elder abuse, (6) home safety/dementia (7) home safety/frailty, and (8) nursing home placement. We utilized Web sites and references noted in these articles (such as the Rosalynn Carter Institute on Caregiving database of RCTs on caregiving (available at <a href="http://www.rosalynncarter.org/caregiver\_intervention\_database">http://www.rosalynncarter.org/caregiver\_intervention\_database</a>) to identify additional references and resources. We excluded studies pertaining related to care provided to adult children with serious or mental illness. Our recommendations were informed by our literature review and our clinical experience caring for older adults and adult caregivers of aging parents.

# **Epidemiology and Prevalence**

Both in the United States and globally, multigenerational living has increased. A 2008 Pew report noted that 16.1% of all US households included 2 adult generations, a 34% increase from 1980.<sup>2</sup> The proportion of those aged 65 years and older living in a multigenerational family household has also increased, from 16.8% in 1990 to 19.6% in 2008. A recent article in the Wall Street Journal speculated that these trends were associated with "the high unemployment rate, the rising cost of nursing-home care, an aging population and a 2006 change in Medicaid law that makes it harder for people who wish to qualify to give away assets." In 2009 the National Alliance of Caregiving surveyed 1297 adults in the US, 18 years of age and older, who were caring for someone 50 years of age and older. Using random digit dialing and other sampling techniques, the authors reported that 50% of caregivers were adult children caring for their parents; 13% of these adult children were actually living with their older parent(s). Intergenerational living arrangements are also common in many other countries, particularly in Asian, African, and Latin American counties (ranging from 4–43% in European countries, to almost 90% in Bangladesh). A

# Before the Move: making the decision

**Mrs.** M: When my husband started to have episodes of not remembering things that he should remember or going off by himself and then not knowing his way back, then I thought it was time...

### The Living Arrangement Checklist, a framework for decision-making

Many circumstances and events can precipitate the need for a transition; thoughtful planning and anticipation of these needs ideally includes input from both the older adult's and adult child's physician. Table 1 offers a checklist of elements to consider prior to changing living arrangements of any kind. For Mr. and Mrs. M, this checklist could have guided them in their decision to move in with their daughter and in considering other living arrangements when their needs changed. A number of online resources, (see Resources) offer additional tools for considering which particular living arrangement would be optimal. Table 2 highlights some of the specific issues that should be considered if moving in with a family member. Evidence suggests that proactive planning can enhance the confidence of

caregivers, reduce caregiver burden and impact on work-related responsibilities, while also improving quality of life and the care aging parents receive. Ideally, physicians should call on other disciplines to provide complementary expertise with community-specific practical advice. Because patients typically have better access to physicians than to social workers or geriatric case managers, physicians benefit from being familiar with resources in their area to refer patients in need of these services.

#### Attending to the parent

Before the transition into the adult child's home, the provider must be attentive to the warning signs that the current living arrangement is no longer appropriate. Common warning signs include: inability to engage easily in IADLS (managing finances, maintaining food and other household supplies); if caring for a physically or cognitively impaired spouse, evidence of caregiver fatigue; and increasing difficulty with mobility. Changes in living arrangements are often precipitated by changes in function<sup>6</sup> and changes in cognition.<sup>7</sup> A functional and cognitive assessment will highlight when priority should be given to discussing potential transitions in living arrangements over discussing more traditional medical issues. In a controlled clinical trial of 153 older adults with Alzheimer disease and their caregivers, older adults assigned to a geriatric nurse practitioner who regularly monitored patient cognitive status and provided written and verbal caregiver education on communication and coping skills and legal and financial advice experienced fewer behavioral and psychological symptoms, and caregivers (36% of whom were adult children) experienced less distress.<sup>8</sup>

Physicians should encourage older patients and/or their adult child caregiver to maintain a personal health record to ease the impact of care transitions. Both paper-based and computer/internet-based personal health records are available (see, e.g., www.caretransitions.org/documents/phr.pdf).

The Health Insurance Portability and Accountability Act (HIPAA) can be a barrier to communication with adult children during care transitions. The Department of Health and Human Services website (http://www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/consumer\_ffg.pdf) educates patients and caregivers about these regulations. Under HIPAA, a doctor may discuss medications, post-procedure treatment plans, and charges with an adult child who has accompanied that patient for treatment. An older adult patient can give oral or written permission to permit health care providers to discuss the patient's condition or care with anyone she chooses. However, providers *may not* give information regarding condition or prognosis if the older parent *objects* to this information being transmitted. There are no clear guidelines regarding information privacy in the setting of diminished capacity in dementia. Older parents and their adult children should be encouraged to contact all of their providers' offices, fill out HIPAA-specific forms, and each keep a copy. According to the HIPAA Privacy rule, "an individual that has been given a health care power of attorney will have the right to access the medical records." 10

## Financial considerations in living arrangements

Mr. and Mrs. M's Son-in-law: So many of the living decisions are made around money, which is an under the table issue...one of the things driving my wife's parents is the notion that they spent their whole life saving this money so they could pass it on to their grandkids. To spend it all living in a nursing home is the last thing they ever wanted to do.

Finances often play a key role in decisions regarding living arrangements. They may also play a significant role in placement choices. Few families have the financial resources to pay for care for ADLs for more than 3–4 years, since such care costs \$75,000–100,000/yr<sup>11</sup> and

the average net worth of an American family at retirement age is  $\sim $543,000.^{12}$  Parents' assets, their credit history, pension benefits and whether or not they have long term care insurance will impact what is available to them. When a parent's assets are depleted in a nursing home setting, the older parent may apply for Medicaid. However, the nursing home must accept Medicaid payment; otherwise the older parent will have to move to a different facility.  $^{11}$ 

#### Preparing the home

Physicians should alert families that the home may require preparation prior to the move; as older adults decline, new modifications will be needed. Although in many instances functional decline is not predictable; <sup>13</sup> in frailty and dementia, it is common to see a stepwise decline in IADLs and ADLs over time. 14 When older parents are independent, minimal adaptive technology may be needed. Important considerations for a frail but otherwise ambulatory older adult include assuring adequate lighting, installing grab bars in baths and showers, and maintaining sturdiness of handrails, especially on stairs. Carpet holes and throw rugs present fall hazards, as do cluttered hallways and living spaces. 15 Increased mobility limitations, as occurred for Mrs. M, may dictate additional modifications: first floor living, wider passage doors, smooth flooring for wheelchair use, and increased hall width. 16 For older parents with dementia, like Mr. M., other modifications are routinely required that address management of wandering, management of incontinence, safety and independence, and reduction of confusion in the home. A number of useful resources exist to guide home modifications for dementia patients (See Resources), including a fact sheet developed at the Alzheimer's Disease, Education and Referral Center. <sup>17</sup> Environmental modifications have a greater impact on functional outcomes than on falls. In a recent narrative review of 29 studies evaluating the impact of environmental modifications on care recipient outcomes, 7 of 13 studies suggested a link between the intervention (often tailored to the care recipient) and improvements in functional ability-related outcomes; fewer studies (only 5 of 18) suggested reduction of falls with environmental modifications. 18

## Managing resistance

Some older parents may resist moving in with their children, and when they move in, they may resist support from paid help, as did Mrs. M. Resistance may stem from a desire to stay in their current familiar setting or from a fear of being a burden. Utilizing the tools of motivational interviewing may facilitate more of a willingness to change (Table 5). The physician and his/her team can assist the adult child and the older parent with the transition by inquiring what ground rules have been set up between the adult children and parents related to family and personal boundaries and privacy. Establishing ground rules prior and during the initial transition can minimize conflict and misunderstanding later. Ground rules may also be necessary regarding how the adult parent interacts with grandchildren in the home.

Physicians should advise patients that adult parents who move in with their adult children are at risk for social isolation, especially if they are far from their community of origin. Identifying avenues for community engagement through social groups, faith communities, or the Internet should be incorporated into the transition plan.

Finding physicians and providers in a new location may prove difficult. The American Geriatrics Society (www.americangeriatrics.org) and the National Association of Professional Geriatric Care Managers (www.caremanager.org) both have provider locators on their Web sites.

## During co-residency: attending to the caregiver

Mr. and Mrs. M's Daughter: I imagined that I could do this easily. ... I was looking forward to the good feeling of creating this sort of different model ... I could see almost no bad side. I didn't prepare myself emotionally at all, except that I prayed a bit.... Over the past 6 months, my mom has become so lonely that she almost can't let me go. One of the hardest things for me is pulling away.

**Mr. and Mrs. M's Son-in-law**: I think the hardest parts have been as my wife's dad has gone from mild cognitive impairment to really moderate stage dementia, currently. It's hard to see your mom fighting against losing her husband on a daily basis. It's a lot easier for that to happen 3,000 miles away because you just don't see it. I don't think that [we] were prepared for how hard that was.

Caring for older parents, while often rewarding, <sup>20</sup> is also demanding and stressful. Over half of caregivers who work full time make workplace accommodations (going in late, leaving early, taking time off during the day). <sup>1</sup> In-home caregiving of adult parents can also lead to tension resulting from divided obligations to the adult child's own family and to their older parent, anger towards siblings for not sharing equally in parent-care activities, and ambivalence regarding the changing roles between the adult child and the older parent. <sup>21</sup> Caregiving can also have negative impact on emotional and physical health<sup>22</sup> and result in social isolation. In a community-based study of 4,041 older adults and baby boomers living in Connecticut, 19% reported providing unpaid care and assistance to a relative or friend. Of these caregivers, over three-quarters (79%) cared for an older relative. Caregivers who coresided with their family members were 2.5 times more likely to feel socially isolated. <sup>23</sup>

As in Mr. and Mrs. M's daughter's case, caregivers (CG) are often surprised by the toll caregiving may take. In a study of 92 adult children (primarily adult daughters) participating in caregiver support groups, CG described their own anxiety or exhaustion related to caregiving tasks, insufficient mastery of caregiving, and ambivalence regarding continuing indefinitely in the role of the caregiver. Identified learning needs included approaches to coping, interacting effectively with their care recipient (CR), accessing resources and ways to minimize harm or danger. <sup>24</sup>

A number of studies in recent years have demonstrated positive effects of CG interventions on both CG stress and institutionalization. Most of these interventions were multidimensional and utilized a combination of family/individual counseling, support group participation, tailored problem solving, and "check-in" telephone calls. In a randomized 5site clinical trial of four hundred ninety-five dementia CG and CR dyads receiving tailored counseling sessions over a 6 month period, CGs reported better self-rated health, sleep quality, physical health, and emotional health, which was related to less burden and bother with their caregiving role than for CGs not receiving the intervention.<sup>25</sup> In a randomized controlled trial of 406 spouse CG of community-dwelling dementia patients receiving tailored counseling and telephone calls, patients whose spouses received the intervention experienced a 28.3% reduction in the rate of nursing home placement compared with usual care controls (hazard ratio = 0.717 after covariate adjustment, p = 0.025). In a prospective 2group randomized trial of 209 patients with dementia-family caregivers dyads at 4 months, 67.5% of intervention caregivers reported improvement in targeted problem behavior, compared with 45.8% of caregivers in a no-treatment control group (P=.002), and fewer intervention caregivers had depressive symptoms (53.0%) than control group caregivers (67.8%, P=.02). Similar caregiver outcomes occurred at 24 weeks but were less apparent at 9 months. <sup>26,27</sup> These interventions are clearly resource intense but highlight the significant benefit counseling and problem solving can accrue. A randomized study of a computerbased psychoeducation program for 52 family caregivers of older adults with Alzheimer's

disease demonstrated significantly higher scores on measures of mastery and distress compared to controls, suggesting that computer and web-based interactive education may also be a reasonable approach for supporting caregivers.<sup>28</sup> It is important for physicians caring for both the older parent and the caregiving child to be aware of potentially intense dynamics, to assess for possible tensions, and consider appropriate referrals for support and counseling. <sup>29,30</sup> Providers may also benefit from having caregiver resources on hand in their office for adult children providing care (see Resources).

In addition to counseling and caregiver support, caregiver burden can be reduced with the use of care extenders in the home, as Mr. and Mrs. M's daughter learned. 31,32 For the most part, these care extenders are not covered by traditional healthcare insurance (e.g., Medicare); with skilled home care service and hospice, home health aides may be able to assist with some IADLS and ADLs as long as the adult parent meets criteria for skilled homecare services. Many states offer homecare and personal care services through their Medicaid waiver program. Eligibility varies by state but generally requires that the CR be sufficiently functionally impaired to meet requirements for nursing home care. Care recipients who have long term care insurance often have options for payment of some long term services in the home. Policies vary greatly, and professional advice (geriatric care manager or legal) is often helpful to assess and navigate benefits. The 2010 Patient Protection and Affordable Care Act (Pub. L. 111–148, 124 Stat. 119) offers voluntary long term care insurance coverage, which will make this type of insurance more available to middle class recipients than it has been in the past. Even with long term care insurance increasingly accessible to older adults, finding high quality personal care services or identifying effective care consultants/manager is often a difficult task. For some caregivers, a time of respite from caregiving may be very valuable. Respite care can come in many forms, from institutional care to adult day care. In a review of studies evaluating the impact of respite, most demonstrated emotional benefit to the caregiver. However, the studies did not consistently demonstrate that respite care delayed entry to residential care or conversely, adversely affected frail older adults receiving the care. 33 Unfortunately, in many parts of the United States, especially in rural areas, respite services may not be readily available.<sup>34</sup>

### Assessing the potential for abuse: a role for physicians of elders and adult caregivers

**Mrs.** M: Now, I'm not saying I don't lose my temper, occasionally. I've talked to one of the priests about that and told him that I'm losing my temper too much [with my husband.] .... That isn't good and I have to work on that....

Mrs. M's confession of her tension is illustrative of the frustration that a spouse or a caregiver may experience, particularly if the family member has dementia. These tensions can lead to abuse by either the caregiver or care recipient. In Mr. and Mrs. M's case, Mr. M actually demonstrated physically aggressive behaviors towards Mrs. M (which in a study of 541 community-residing dementia patients occurred 15% of the time in the 2 weeks prior). While negative feelings may be part of normal day-to-day conflicts, the medical team should still regularly monitoring for elder abuse and educate the caregiver in constructive responses.

Elder abuse affects between 1 and 2 million older adults are affected each year.<sup>36</sup> The National Elder Abuse Incidence Study revealed that 36.7% of substantiated incidents of elder abuse were perpetrated by the adult children of the victims, with family members and spouses ranked as the next most likely abusers.<sup>37</sup> Risk factors for abuse include caregiver stress, cognitive impairment and need for assistance in activities of daily living of the care recipient, brittle social support, and history of abusive behavior on the part of the care recipient.<sup>38</sup> Other risk factors include a history of a poor relationship between the caregiver and care recipient and a history of substance abuse by the caregiver.<sup>39</sup> Questions to ask the

older parent may include those in Box 1. If elder abuse is suspected (see Table 3), all health care providers (physicians, nurses, social workers, etc.) and administrators are mandated by law to report it to state or county adult protective services.

#### Box 1

#### Questions to consider when assessing for elder abuse

Has anyone at home ever hurt you?

Has anyone made you do things you didn't want to do?

Has anyone ever threatened you or made you feel afraid?

Has anyone taken something that was yours without asking?

Have you ever signed a document you didn't understand?

### **Evolving functional decline and subsequent care transitions**

Mr. and Mrs. M's Son-in-Law: My wife's mother was completely independent in all her activities of daily living. ... Her daily circuit was Mass, shopping, then home. .... Her dad was completely independent. ... Over 4 years he has become dependent ...: he can't dress himself, he can't groom or bathe himself, and he's become intermittently incontinent...

**Mr. and Mrs. M's Daughter** My mother's social network was my dad. They were very, very close. I think this has been more isolating than any of us thought. I can see real advantages to a retirement community. I've come full circle on it.

Another level of care is often required when caregivers are no longer able to provide care in the home setting, or when the older adult identifies gaps in their care that can best be addressed in a different setting. In a systematic review of factors leading to nursing home placement, severity of cognitive impairment, functional needs, behavioral issues and depression increased likelihood for nursing home placement. <sup>40</sup> Caregiver issues also played a key role; caregivers who experienced greater emotional stress or feelings of being "trapped" in care responsibilities were more likely to institutionalize persons with dementia. Demographic variables, incontinence, and service use did not consistently predict nursing home admission. The actual type of care setting will largely be dependent on the older adult's functional status and financial resources. <sup>11</sup>

For patients whose prognosis is less than six months (if the illness were to run its normal course), and who demonstrate functional decline, home hospice may be appropriate. Adult children providing care may be so close to the situation that they may not notice the level and severity of decline. The patient's physician may be able to provide useful insights regarding the need for hospice. It is important for physicians to recognize that grieving may take on a more intense nature when the parent dies, due to the parent's routine presence in the adult child's home. Formal acknowledgement of a change in the setting of care or death of the care recipient may play a therapeutic role in the caregiver's grief process. The adult caregiver will likely greatly appreciate a sympathy note from the provider upon the death of the parent. A2,43

#### Conclusion

The decision by older parents and an adult child to live together is rarely a straightforward one. It can be both mutually enriching and also serve as a source of isolation for the older parents and stress for the adult child. Given the increasing prevalence of this living

arrangement, physicians can expect to be called on for guidance with greater frequency. Physicians can help mitigate the negative impact of these transitions by assuring an up-to-date health record with current measures of function and cognition, working with older parents and adult children to assess the pros and cons of various living arrangements, and making appropriate referrals to professionals knowledgeable about the financial and social implications of any move. During co-residency, attention to caregiver stress and modalities for caregiver support become paramount. The physician also needs to be attentive to clues for possible elder mistreatment. Finally, when it is clear that different living arrangements or health care services are required, physicians can gently assist the older parents and adult child in planning and navigating the new transition.

## **Acknowledgments**

The authors would like to thank the family and physician who generously shared their stories. Christine Ritchie is on the Board of the American Academy of Hospice and Palliative Medicine. Dr. Ritchie is supported by a Geriatric Academic Leadership Award from the National Institute on Aging (1K07AG31779), R01 AG015062, UB4HP19045, and R18-HS017786-02. Richard Allman is supported by Award Numbers R01 AG015062, P30AG031054, and 5UL1RR025777. The content is solely the responsibility of the authors and does not necessarily represent the official views of the the National Institutes of Health or any other sponsor.

#### References

- Barrett, LL. Caregiving in the USA Focused Look at Those Caring for Someone Age 50 or older. National Alliance for Caregiving; 2009. http://www.caregiving.org/data/ FINALRegularExSum50plus.pdf [Accessed January 1, 2009]
- [Accessed November 20, 2010] Pew Research Center Social & Demographic Trends report. The Return of the Multi-Generational Family Household. Mar 18. 2010 http://pewsocialtrends.org/files/ 2010/10/752-multi-generational-families.pdf
- Tergesen, A. [Accessed June 10, 2011] Should you pay a relative to take care of your mom?. Wall Street Journal. Dec 11. 2010 http://online.wsj.com/article/ SB10001424052748703963704576005892803914056.html?mod=googlenews\_wsj
- 4. United Nations. Living arrangements of older persons around the world. New York: United Nations, Department of Economic and Social Affair, Population Division; 2005.
- Parker MW, Call VR, Toseland R, Vaitkus M, Roff L, Martin JA. Employed Women and Their Aging Family Convoys: A Life Course Model of Parent Care Assessment and Intervention. J Gerontol Social Work. 2003; 40:101–121.
- Miller EA, Weissert WT. Predicting Elderly People's Risk for Nursing Home Placement, Hospitalization, Functional Impairment, and Mortality: A Synthesis. Med Care Res Rev. 2000; 57(3):259–297. [PubMed: 10981186]
- 7. Kendig H, Browning C, Pedlow R, Wells Y, Thomas S. Health, social and lifestyle factors in entry to residential aged care: an Australian longitudinal analysis. Age Ageing. 2010; 39(3):342–9. [PubMed: 20233734]
- Callahan CM, Boustani MA, Unverzagt FW, Austrom MG, Damush TM, Perkins AJ, Fultz BA, Hui SL, Counsell SR, Hendrie HC. Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: a randomized controlled trial. JAMA. 2006; 295(18):2148–2157. [PubMed: 16684985]
- 9. Coleman EA, Smith JD, Frank JC, Min S, Parry C, Kramer AM. Preparing Patients and Caregivers to participate in care delivered across settings: The care transitions intervention. J Amer Geriatr Soc. 2004; 52(11):1817–1825. [PubMed: 15507057]
- 10. U.S. Department of Health & Human Services. [Accessed June, 2011] Health Information Privacy. http://www.hhs.gov/ocr/privacy/hipaa/faq/right\_to\_access\_medical\_records/220.html
- 11. Kane RL. Finding the Right Level of Care: "We didn't realize that there was any other option for him". JAMA. 2011; 305(3):284–293. [PubMed: 21245184]
- 12. Bucks BK, Kennickell AB, Mach TL, Moore KB. Changes in U.S. Family Finances from 2004 to 2007: Evidence from the Survey of Consumer Finances. Fed Res Bull. 2009:A1–56.

13. Gill TM, Gahbauer EA, Han L, Allore HG. Trajectories of disability in the last year of life. N Engl J Med. 2010 Apr 1; 362(13):1173–80. [PubMed: 20357280]

- 14. Sauvaget C, Yamada M, Fujiwara S, Sasaki H, Mimori Y. Dementia as a predictor of functional disability: a four-year follow-up study. Gerontology. 2002 Jul-Aug;48(4):226–33. [PubMed: 12053112]
- 15. Gillespie LD, Robertson MC, Gillespie WJ, Lamb SE, Gates S, Cumming RG, Rowe BH. Interventions for preventing falls in older people living in the community. Cochrane Database of Systematic Reviews. 2009; (2)
- [Accessed June, 9, 2011] Fair Housing Act Design Manual. 1998. http://www.mitfile.com/pdf/fair-housing-act-design-manual.html
- Alzheimer's Disease, Education and Referral Center. [Accessed June, 2010] Home Safety for People with Alzheimer's Disease. http://www.nia.nih.gov/Alzheimers/Publications/ homesafety.htm
- 18. Wahl HW, Fänge A, Oswald F, Gitlin LN, Iwarsson S. The home environment and disability-related outcomes in aging individuals: what is the empirical evidence? Gerontologist. 2009 Jun; 49(3):355–67. [PubMed: 19420315]
- 19. Rollnick S, Heather N, Bell A. Negotiating behaviour change in medical settings: The development of brief motivational interviewing. J Ment Health. 1992; 1(1):25–37.
- Koerner SS, Kenyon DB, Shirai Y. Caregiving for elder relatives: which caregivers experience personal benefits/gains? Arch Gerontol Geriatr. 2009 Mar-Apr;48(2):238–45. [PubMed: 18336932]
- 21. Sherrell K, Newton N. Parent care as a developmental task. Families in Society: The Journal of contemporary Human Svc. 1996; 77:174–181.
- 22. Pinquart M, Sörensen S. Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. Psychology and Aging. 2003; 18(1):250–267. [PubMed: 12825775]
- 23. Robison J, Fortinsky R, Kleppinger A, Shugrue N, Porter M. A broader view of family caregiving: effects of caregiving and caregiver conditions on depressive symptoms, health, work, and social isolation. J Gerontol B Psychol Sci Soc Sci. 2009; 64(6):788–98. [PubMed: 19318470]
- 24. England M. Expressed information and resource needs of filial caregivers reporting recent experiences of crisis. Educat Gerontol. 2001; 27:139–157.
- Elliott AF, Burgio LD, Decoster J. Enhancing caregiver health: findings from the resources for enhancing Alzheimer's caregiver health II intervention. J Am Geriatr Soc. 2010 Jan; 58(1):30–7.
   [PubMed: 20122038]
- 26. Gitlin LN, Winter L, Dennis MP, Hodgson N, Hauck WW. A biobehavioral home-based intervention and the well-being of patients with dementia and their caregivers: the COPE randomized trial. JAMA. 2010 Sep 1; 304(9):983–91. [PubMed: 20810376]
- 27. Gitlin LN, Winter L, Dennis MP, Hodgson N, Hauck WW. Targeting and managing behavioral symptoms in individuals with dementia: a randomized trial of a nonpharmacological intervention. J Am Geriatr Soc. 2010 Aug; 58(8):1465–74. [PubMed: 20662955]
- 28. Hepburn K, Lewis M, Tornatore J, Sherman CW, Bremer KL. The Savvy Caregiver program: the demonstrated effectiveness of a transportable dementia caregiver psychoeducation program. J Gerontol Nurs. 2007 Mar; 33(3):30–6. [PubMed: 17378189]
- 29. Covinsky KE, Eng C, Lui LY, Sands LP, Sehgal AR, Walter LC, Wieland D, Eleazer GP, Yaffe K. Reduced employment in caregivers of frail elders: Impact of ethnicity, patient clinical characteristics, and caregiver characteristics. Journals of Gerontology: Medical Sciences. 2001; 56(11):M707–M713.
- 30. Kang SY. Predictors of Emotional Strain Among Spouse and Adult Child Caregivers. J Gerontol Social Work. 2006; 47(1–2):107–131.
- 31. Chan N, Anstey KJ, Windsor TD, Luszcz MA. Disability and depressive symptoms in later life: the stress-buffering role of informal and formal support. Gerontology. 2011; 57(2):180–9. [PubMed: 20424429]

32. D'Souza JC, James ML, Szafara KL, Fries BE. Hard times: the effects of financial strain on home care services use and participant outcomes in Michigan. Gerontologist. 2009 Apr; 49(2):154–65. [PubMed: 19363011]

- 33. Mason A, Weatherly H, Spilsbury K, Golder S, Arksey H, Adamson J, Drummond M. The effectiveness and cost-effectiveness of respite for caregivers of frail older people. J Am Geriatr Soc. 2007; 55(2):290–9. [PubMed: 17302669]
- 34. Whittier S, Scharlach AE, Dal Santo TS. Availability of caregiver support services: implications for implementation of the National Family Caregiver Support Program. J Aging Soc Policy. 2005; 17(1):45–62. [PubMed: 15760800]
- 35. Lyketsos CG, Steele C, Galik E, Rosenblatt A, Steinberg M, Warren A, Sheppard JM. Physical aggression in dementia patients and its relationship to depression. Am J Psychiatry. 1999 Jan; 156(1):66–71. [PubMed: 9892299]
- 36. Elder Mistreatment: Abuse, Neglect and Exploitation in an Aging America. Washington, DC: National Research Council Panel to Review Risk and Prevalence of Elder Abuse and Neglect; 2003.
- 37. Tatara, T.; Kuzmeskus, LM. National Center on Elder Abuse: National Elder Abuse Incidence Study. American Public Human Services Association; Washington, D.C: 1997. Trends in elder abuse in domestic settings.
- 38. Wiglesworth A, Mosqueda L, Mulnard R, Liao S, Gibbs L, Fitzgerald W. Screening for abuse and neglect of people with dementia. J Am Geriatr Soc. 2010 Mar; 58(3):493–500. [PubMed: 20398118]
- Aravanis SC, Adelman RD, Breckman R, Fulmer TT, Holder E, Lachs M, O'Brien JG, Sanders AB. Diagnostic and Treatment Guidelines on Elder Abuse and Neglect. Arch Fam Med. 1993; 2:371–388. [PubMed: 8130916]
- 40. Gaugler JE, Yu F, Krichbaum K, Wyman JF. Predictors of nursing home admission for persons with dementia. Med Care. 2009; 47:191–8. [PubMed: 19169120]
- 41. Lynn J. Serving patients who may die soon and their families: the role of hospice and other services. JAMA. 2001; 285:925–932. [PubMed: 11180736]
- 42. Main J. Improving management of bereavement in general practice based on a survey of recently bereaved subjects in a single general practice. Br J Gen Pract. 2000; 50:863–866. [PubMed: 11141870]
- 43. Bedell SE, Cadenhead K, Graboys TB. The doctor's letter of condolence. N Engl J Med. 2001 Apr 12; 344(15):1162–4. [PubMed: 11302139]

Table 1

Living Arrangement Planning Checklist

Components	Potential Parties Involved	Specific Tasks
<u>Medical</u>	Primary care provider Geriatrician Geriatric care manager Social worker Older parent and parent-selected adult children	Assure an up-to-date health record with active conditions, current functional and cognitive status, medications, providers, and advance directive; obtain records related to key hospitalizations and diagnostic procedures.      Estimate future environmental and functional needs, based on current functional and cognitive status and observed rates of recent decline.      Identify whether new location has adequately qualified healthcare personnel to meet the older adult's healthcare needs.      Identify whether new living arrangement can accommodate functional and cognitive limitations.      Assure presence of appropriate signatures for HIPAA-related disclosure.
Legal/Financial	Elderlaw attorney Accountant Geriatric care manager Older parent and parent-selected adult children	<ul> <li>Clarify living arrangement preferences (type of long term care setting, preferred distance to specific family members, if applicable).</li> <li>Identify assets and liabilities associated with a particular living arrangement (see long term care savings calculator at http://www.longtermcare.gov/LTC/Main_Site/Planning_LTC/Considerations/).</li> </ul>
Spiritual	Spiritual advisors Older parent and parent-selected adult children	Identify whether relevant religious services/communities are available in the new location being considered.
Social	Older parent and parent-selected adult children Social worker	Note important activities in which the older adult(s) currently engages and how these activities will be affected by a move.

#### Table 2

#### Issues to Address When an Older Parent Moves in with an Adult Child

• Finances – Contributions from the parent(s), siblings, others

Costs of any home renovations

Tax implications

- · Adequacy of space in children's home
- Impact on others living in the home spouse, significant others, children
- · Necessary home modifications
- Need for durable medical equipment
- · Caregiving needs and who will provide them
- Household rules and expectations
- · Expectations of parent and adult children regarding roles and responsibilities
- Impact on prior relationships in the family (e.g. previous marriages, etc)
- Impact on spouse's parents or other older adults for whom the child/spouse may be providing care
- Impact on adult children's children, especially if they are still living in the home
- Availability of community resources where the child lives (legal, financial, spiritual or religious communities, family and friends, other sources of emotional and social support, well-trained health care professionals with competencies in caring for the special needs of older adults)

### Table 3

# Cues for Elder Abuse

Туре	Cues	
Emotional	Evidence of fearfulness or increasing social isolation	
Physical	Bruises or grip marks around the arms or neck Repeated unexplained injuries	
Financial	Large withdrawals from bank accounts, switching accounts, unusual ATM activity	
Neglect	Inadequate hygiene Pressure ulcers, unexplained weight loss	

Adapted from materials from the National Center for Elder  $\mbox{Abuse}^{44}$ 

Table 4

# Advance Care Planning beyond Advance Directives

Topic	Words to Say
Support with transportation	Have you thought about how you will know when it is no longer safe to drive?  What options do you have for getting to the doctor or to the grocery store if you are no longer able to drive?
Support with finances	If you were to need help with managing your checkbook, who would you turn to for help?
Support with medication management	If you were to need help with managing your medications, who would you turn to for help?
НІРАА	Beside yourself, who would you want to make sure we could contact and communicate with about your medical condition?

 $\label{eq:Table 5}$  Words to Say when there is resistance about Changing Setting of Care  $^{45}$ 

Actions	Words to Say
Ask open questions	What are your concerns about making a move? Tell me what you are worried about when you think about moving.
Provide affirmation (point out strengths and build rapport)	So you are taking control of your life by taking stock and thinking about the future.
Engage in reflective listening (demonstrate respect and allow for creative problem- solving)	You see the benefit of moving but are afraid of losing your independence.
Summarize (maintain direction and momentum towards consideration of a change)	"Let me stop and summarize what we've just talked about. You're not sure and only agreed because your daughter insisted on it. At the same time, you've had some nagging thoughts of your own about what's been happening, including how safe it is to live by yourself now that you have fallen twice. You want to remain in control and worry that with a move you will lose your independence. Did I miss anything?"