When to put a parent in assisted living or a nursing home

Elliott S. Levy
Bentley University

Abstract

This paper provides an overview of assisted living facilities and nursing homes. Major points presented include the definition of an assisted living facility; an historical overview of nursing homes; sources of financing for alternative housing arrangements, including Medicare and Medicaid; and descriptions and guidelines for Activities of Daily Living (ADL). The paper raises psychological and emotional concerns and concludes with the recognition that the "sandwich generation" has a difficult task in deciding how and where a parent is going to live.

Keywords: Assisted living, activities of daily living, nursing homes, medicare, medicaid

Introduction

Much has been written about alternative housing for seniors. What is available? What are the costs? An issue that deserves more attention is the reality of making the decision by or for a senior to change his or her housing arrangement. This decision is affected by the options available, the differing finances, and – perhaps most importantly – the emotional and psychological implications of the decision. Seniors who have children often give their children the right to make decisions on their behalf by preparing a durable power of attorney and an advance-care health directive, or similar documents. When and how the children exercise their responsibility in regard to housing are not easy questions to answer. This paper will present a discussion of several related questions including: When should the attorney-in-fact decide to move a parent into a housing arrangement that provides some assistance with activities of daily living (i.e., assisted living)? What if the parent refuses? How does one evaluate how well the parent manages the activities of daily living (ADL), which include bathing, dressing, moving and feeding oneself; or cognitive impairment or other mental issues? What is the role of the physician? In addition to financial concerns, what are the psychological factors affecting this decision?

Options

Living independently is something many take for granted, whether a senior or not. Many if not most people move out of their parents' home and "live independently" sometime in their lives. Based on a 1998 survey, most believe that both men and women should leave home between the ages of 18 and 25 (Settersten, 1998). Does "independently" mean without financial help or without physical help? To most seniors, it means living in one's own home (house, apartment, condo, whatever). The children or others may be helping financially and there may even be an arrangement for someone to help periodically – such as a child or hired aid coming 2-3 days a week for 4 hours a day to help with chores, doctors' visits, etc – or regularly, such as a live-in child or aid who may assist with daily living activities. Regardless, the senior feels in control, and is in his or her home whether the home is a house in a retirement community, an expatriate enclave outside of the United States, an apartment in the Bronx, or an oceanside condo in Florida. It is not in a room in the children's home. It is not in a community where the resident is subject to rules that affect basic choices – real or imagined – about decisions such as food, transportation, pets, relationships, and conjugal visits.

An assisted living facility, which has surfaced as an alternative living arrangement, can be defined as "a form of housing arrangement that provides some assistance with activities of daily living" (Weisman, 2004, p. 246) or more broadly as group housing with additional services (Hedrick, et al., 2007), or more specifically as "a facility that provides housing, some level of personal care, and some form of health center for people who need assistance with activities of daily life such as bathing, dressing, eating, mobility, and personal hygiene, but who do not require the level of services provided in a nursing home (Weisman, 2007, pp. 118-119). A distinguishing characteristic is that the help with activities of daily living (ADL) occurs at the "facility," a term that could make any senior shudder! The term sounds like a controlled environment and it is - at least relative to one's own home. According to the Assisted Living Federation of America (http://www.alfa.org), "The variety of settings, care offerings, and residences can range from convenient high-rise apartments near metropolitan centers to converted Victorian homes, to campus communities with all the charms of a small town. There is

no single blueprint for assisted living because consumers' preferences and needs vary widely. Most residences have between 25 and 120 units, varying in size from a single room to a full apartment. They may be operated by nonprofit or for-profit organizations." There can be varied living arrangements regarding type of housing (apartment, house, roommate), eating choices (dining room vs. one's own space), transportation (to appointments and other external activities), and social activities (inside and outside of the "facility"). The commonality is that one is giving up his or her "independent" living and thus some independence, and perhaps a lot of self-esteem, in exchange for readily accessible (hopefully) assistance with ADL. This may be very comforting to loved ones such as the senior's children, but it may be a nail in the coffin of an elder.

In comparison to the fairly recent advent of assisted living facilities, nursing homes have existed in the United States from the early 1900's when most states sent their impoverished citizens to "poor farms" or "almshouses." The history of nursing homes is filled with legislation, regulation and scandal. The New Deal in the 1930s and the Social Security Act of 1935 helped start the development of private old-age homes. Legislation in the 1950s (amendments to the Social Security Act), 1960s (Moss Amendments), 1970s (Miller Amendment), and 1980s (Boren Amendment) led to a major overhaul of federal regulations for nursing homes in the Omnibus Reconciliation Act of 1985 and repeal of the Boren Amendment in 1997 (http://www.pbs.org/newshour/health/nursinghomes/timeline.html). The very term "Nursing Home" may bring images of a run-down, neglected space inhabited by non-caring staff and patients reminiscent of Jack Nicholson in One Flew Over the Cuckoo's Nest (1975). Such was the reality for many nursing homes and may, in fact, be true in some cases today. The thought of being put into a nursing home would likely be greeted very negatively by a senior. It sounds like one step away from a hospice, or the end of life. Florida is sometimes jokingly referred to as "God's Waiting Room" (see Zagier, 2003); nursing homes, for many, evoke that vision as well. Some nursing homes – or sections thereof - in effect are operating as rehabilitation centers, with some transient residents who are there short-term. Other nursing homes, like hospices, serve as the final living place with only one way out - death. That sounds ominous and, in many a senior's mind, it may very well be the truth.

There are living arrangements that combine parts of independent living, assisted living and nursing homes. Continuing care retirement communities represent a structure that offers varying levels of support from a senior living on his or her own in terms of physical space and most daily decisions; to assisted living where the resident receives help with ADL; to full support as is found in a nursing home. A distinguishing characteristic of these communities – which prefer not to be called "facilities" (based on a conversation with a representative of a "senior living campus" who kept correcting the caller who used the incorrect term) – is that a resident can transition across the varying levels of care without leaving the community.

Financial issues

The alternative housing arrangements raise different financial concerns. Owning vs. renting is an issue. Entrance fees and recurring monthly, quarterly, or annual fees are another concern. What is included in the costs charged by a facility or community? Is there exposure to subsequent increases in costs? What is the role of Medicare and Medicaid and long-term care insurance? These are some of the more important financial questions.

Medicare, which is a national insurance program for Social Security recipients who are at least 65 or disabled, will pay fully for 20 days of nursing home care and then partially pay for the next 80 days with the resident responsible for a copayment (Weisman, 2004, p. 178). The current "Skilled Nursing Facility Coinsurance" is $128.00 per day for days 21 through 100 each benefit period (www.medicare.gov). Medicaid, which is a joint federal and state program, is the only public program available to pay for long-term nursing home care (Weisman, 2007, p. 207). According to the United States Department of Health and Human Services, the 2010 estimated costs for nursing home care will total $151,171million (36% or $54,656 million from private funds, 45% or $67,368 million from federal government Medicare and Medicaid payments, and 19% or $29,157 million from state and local governments Medicaid payments) (http://www.cms.hhs.gov/NationalHealthExpendData/03_NationalHealthAccountsProjected).

In making the decision to move a senior to alternative housing, costs will vary significantly and all costs must be researched and evaluated. Resources to cover those costs can be generated from various sources. Eligibility for Medicaid is a complex question, with rules changing every 7-10 years (Weisman, 2007, p. 209). Accordingly, it is advisable to consult with professionals experienced in Medicaid law. Regarding private resources, individuals can look to their personal assets including their home, which can be sold or rented out. A home equity loan or reverse mortgage may also be secured. Long-term care insurance, if owned, could be a major source of funding. Life insurance can provide funds by the owner cancelling a policy with cash surrender value, borrowing against the insurance policy, tapping into accelerated death benefits, or selling the policy (viatical settlements). Deferred annuities that may be owned might be accessible early with no penalty. A disability insurance policy may be exchangeable for a long-term care insurance policy (Weisman, 2007, pp. 129-158).

Activities of daily living

When discussing alternative housing arrangements, one must consider the degree to which the elder can perform activities of daily living (ADL). These activities typically include bathing, dressing, moving and feeding oneself. The extremes of being fully capable and totally incapable would be apparent to most people. It is everything in between that has some subjectivity involved. A physician, occupational therapist or social worker might be best able to judge, and, in many hospitals and rehabilitation centers they may be the individuals who individually or jointly make the judgment. But even their assessment may be subject to challenge, especially by the individual being judged. If an individual cannot bathe oneself does he or she need assistance on a daily basis? Does one have to be able to hold a cup without shaking in order to be deemed able to feed oneself? Is using a walker or wheelchair the deciding factor as to whether one is capable of moving without assistance?

In assessing a senior's ability to perform ADL, one can find several tools in the medical and geriatric literature such as the Northwick Park Dependency Score (Plantinga et al., 2006), the Care Dependency Scale (Plantinga et al., 2006), and the FIM(TM) (Wright, 2000). The Barthel Activities of Daily Living Index (Barthel Index) is referenced often and is highly recommended, although some uncertainties regarding reliability when used with older people have been raised (Sainsbury et al., 2005). The Barthel Index consists of ten items – feeding, bathing, grooming, dressing, bowels, bladder, toilet use, transfers (bed to chair and back), mobility (on level surfaces) and stairs. Scores are attached to responses and ranges are

established for different levels of independence. For example, 80-100 is the independence range for men (Terry et al., 2008).

Although there may be some specific, objective guidelines to help physicians and others to make this call, there appears to be a lot of subjectivity and professional judgment involved. Also, in addition to assessing the ability to perform ADL, judgment has to be used to evaluate a senior's cognitive impairment or other mental issues. An issue to consider is whether or not children are in a position to assess a parent's ability to perform activities of daily living. Are they able to determine how much assistance is needed? Could children be facing conflicting interests such as when concern for the parent raises issues about their lives and their responsibilities to spouses and/or children? An overriding concern is the assessment made by the senior - assuming that the senior is of sound mind, which is yet another judgment that has to be made. Do we turn to lawyers and judges to determine if one is "of sound mind"?

Psychological factors

"I've fallen and I can't get up," a popular phrase of the early 1990s based upon a line from a television commercial (http://www.retrojunk.com/details_commercial/1087/), are words a senior's child fears hearing. Falls can change many people's lives, particularly seniors. This often marks a changing point. An individual who was able to live independently and manage to perform ADL either alone or with the limited twice or three times a week help of a child or aid, suddenly needs a walker, cannot dress him or herself, etc. A stroke can have the same effect. Is more help with ADL needed? Is it time to move on to assisted living or a nursing home?

It is difficult for most people to accept the limitations brought on by aging, injury, illness or disease. The stages of grief listed by Kubler-Ross in her 1969 book *On Death and Dying* include denial, anger, bargaining, depression, and acceptance (Verghese, 2004). These stages may very well apply to the process a senior goes through. It would not be unreasonable to expect a senior to have to go through the denial, depression, and anger stages and to mourn the loss of control and independence brought on by age, injury, illness or disease. Self-esteem, self-worth, and self-respect may be falling as well.

The reality of where and how a senior is to live becomes a big issue. "Shoot me before putting me in a nursing home" was overheard from one senior speaking with her children. "She'd never go to assisted living" was attributed to a sister when referring to her elder sibling who was soon to leave a rehabilitation center. Comments such as these are common. They express the difficulty in moving from independent living to any other housing arrangement. These feelings cannot be ignored but neither can the unfortunate choices that have to be made if one loses the ability to manage everyday activities.

How does a child help a parent make a choice? This is not an uncommon dilemma. If a power of attorney gives the child the right to make a choice, then it is his or her responsibility to act in the best interests of the parent and to select an arrangement that will provide the safest and most comfortable setting for the parent. If the child does not have the right, then he or she is motivated by the same objectives. The issue is how to get the senior to make the same choice, given that the senior may be the only one legally empowered to make that choice.

It is important to recognize the issues confronting the parent and to be as supportive as possible. The parent may not accept his or her changing abilities. He or she may be angry, depressed, and even entertaining suicidal thoughts. The child should consider enlisting the help of others. Trusted professionals, including the senior's physicians, occupational and physical

therapists, social workers, and psychologists could confer with the senior individually and/or jointly. Family members and friends could play a role. Even the hairdresser can be influential. If these concerned people can present a consistent stream of recommendations that basically conclude that the time has come for the senior to consider alternatives to the type of independent living that he or she has grown accustomed to, then there is a strong likelihood that change will be easier to make and it will ultimately be the senior's decision. The advantages of a continuing care retirement community, assisted living or a nursing home need to be highlighted. A temporary arrangement may be possible where the senior is able to try a community or facility or home before making a more substantial commitment. The child could stay in the senior's area of the country for that temporary period, if possible, or entice the parent to select a housing arrangement in the child's area – even if in a colder climate!

Conclusion

The sandwich generation (Grundy and Henretta, 2006) has sent their kids off on their own, hopefully, and are now becoming caretakers for their parents. One of the difficult tasks to confront is where and how that parent (or parents) is going to live. As the parent ages, there is a greater likelihood that he or she will be less able to live by him- or herself. The housing alternatives available to accommodate the senior and their costs are factors that must be considered in reaching a decision. The emotional and psychological issues that are raised in the housing decision are of utmost concern. The child must be aware of what a senior is going through as their abilities and independence are diminished. This is not an easy time. If the child lives long enough, there is a strong likelihood that he or she will be on the "senior" end of the issue. Let's hope the child's child successfully manages these decisions.

References

Grundy, E., and J.C. Henretta: 2006, "Between elderly parents and adult children: a new look at the intergenerational care provided by the `sandwich generation'," *Ageing and Society* 5 26, 707-722.

Hedrick, S., M. Guihan, M. Chapko, L. Manheim, et al.: 2007, "Characteristics of Residents and Providers in the Assisted Living Pilot Program." *The Gerontologist* 47.3, 365-77.

Plantinga, E., L. J. Tiesinga, C. P. van der Schans, and B. Middel: 2006, "The criterion-related validity of the Northwick Park Dependency Score as a generic nursing dependency instrument for different rehabilitation patient groups," *Clinical Rehabilitation* 20.10, 921-6.

Sainsbury, A., G. Seebass, A. Bansal, and J. B. Young: (2005), "Reliability of the Barthel Index when used with older people," *Age and Ageing* 34.3, 228-32.

Settersten Jr, R. A.: 1998, "A time to leave home and a time never to return? Age constraints on the living arrangements of young adults," Social Forces 76.4, 1373-1400

Terry, D. F., P. Sebastiani, S. L. Andersen, and T.T Perls: 2008, "Disentangling the Roles of Disability and Morbidity in Survival to Exceptional Old Age," *Archives of Internal Medicine* 168.3, 277.

Verghese, A.: 2004. "On Death and Dying." *Wall Street Journal* [New York, N.Y.] 31 Aug. 2004, Eastern edition: A.12.

Weisman, S.: 2007, *Boomer or Bust* (Pearson Education, Inc. Publishing as Prentice Hall, Upper Saddle River, NJ)

Weisman, S.: 2004, *A Guide to Elder Planning* (Pearson Education, Inc. Publishing as Prentice Hall, Upper Saddle River, NJ).

Wright, J. (2000). The FIM(TM). *The Center for Outcome Measurement in Brain Injury.* http://www.tbims.org/combi/FIM (accessed March 31, 2008).

Zagier, A. S.: 2003, "Eyeing Competition, Florida Increases Efforts to Lure Retirees But Critics Say: First, A Better Infrastructure :[Third Edition]." *Boston Globe* [Boston, Mass.] 26 Dec. 2003,A.3.

http://alfa.org/i4a/pages/index.cfm?pageid=3278 (accessed March 31, 2008)

http://www.medicare.gov/Default.asp (accessed March 31, 2008)

http://www.cms.hhs.gov/NationalHealthExpendData/03_NationalHealthAccountsProjected.asp#TopOfPage (accessed March 31, 2008).

http://www.pbs.org/newshour/health/nursinghomes/timeline.html (accessed March 31, 2008).

http://www.retrojunk.com/details_commercial/1087/ (accessed March 31, 2008).