

Solo Seniors and the Quest to Create a Backup Plan

A WHITE PAPER

BY LINDA J. CAMP

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Introduction

The graying of the population has been a constant theme in public discourse for more than a decade. Countless news stories have focused on the increasing numbers and what they mean, speculating on everything from the adequacy of retiree savings to the need for senior housing. But now that leading edge Baby Boomers have begun to turn 70, conversations are shifting to an entirely different subject—preparing for the end of life. As 2016 began, “end of life” coalitions and initiatives could be found across the United States, in Tucson, AZ, Seattle, WA, Delaware, North Carolina, Washington State, Westchester County, NY; Montgomery County, MD; Chicago, IL, and Southeast Wisconsin, to name just a few.

Talking about “the last chapter” isn’t easy for anyone, but for a growing subsector it is especially difficult. These are individuals who, by choice or circumstance, are without the traditional family support structure. When crafting wills, trusts, Powers of Attorney and Advance Care Directives, members of this group struggle with who to designate as a surrogate. No one has quite figured out what to call them yet, but the most often heard terms are “elder orphans” and “solo seniors.” In this discussion the latter term—solo seniors--will be used because the word “orphan” suggests there are no family members in the picture at all. That’s not always the case. More about this later.

The large group of solo seniors has emerged in the United States for a number of reasons:

- ***People are living longer.*** The National Vital Statistics Center reports that males born in 2009 can expect to live to be age 76; females age 80.9¹
- ***People are having fewer children or no children at all.*** The National Center for Health Statistics reported an average fertility rate of 2.1 in 2012 compared with 3.7 in 1960. ²
- ***People are more mobile than in the past.*** According to the US Census Office, “the US population is characterized by high mobility. In 2010, about 27 % of people were born outside their state of residence.³ Parents and children don’t necessarily live close to one another anymore.
- ***People are making different choices about living arrangements.*** As of 2014, an estimated 28% of all households were individuals living alone. More than half of these

were occupied by individuals *aged 50 or older*. Some 34% of all households were composed of non-family members. More than half of those nonfamily households were made up of individuals *aged 50 or older*⁴

Finally, there are and will continue to be a large number of solo seniors in the US because there are simply more older adults overall—a projected 88 million people age 65 and older by 2050.⁵

The disconnect between the needs of solo seniors and the available late life and end-of-life tools and systems is just beginning to show up in work and thinking about an aging population. Traditional assumptions about the availability of family can be found everywhere, including the most noteworthy research. A good example is the 2014 Institute of Medicine study, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*.⁶ The following is a theme running throughout.

*“Ideally, health care harmonizes with social, psychological, and spiritual support as the end of life approaches. To achieve this goal, care near the end of life should be person-centered, **family-oriented**, and evidence based.”⁶*

The gap that cries out for the most attention is the lack of clear and workable options for health care surrogates. If family members are not part of the picture, who will assist with decisions or serve as the proxy?

The medical community is a major stakeholder in the answer to that question. Past studies have reported that 16% of seriously ill patients in some intensive care units have no one to speak for them.⁷ Consequently a very specific segment of solo seniors is now receiving scrutiny. Often called “unbefriended elders,” these are people for whom planning is no longer possible--individuals who lack or have limited capacity to make their own health care decisions and have no one—neither legally authorized or de facto—to serve as a surrogate.⁸ This contrasts with the solo seniors who are well positioned to plan for later life but don’t know whom to designate.

That is not to say that this emphasis is wrong, for there will always be a need to protect the most vulnerable members of society. Rather, the point is that the current scope is an incomplete one. There are and will continue to be a great many solo seniors leading full and active lives. Though Baby Boomers have a reputation as procrastinators, more and more of them are seeing the need to take affirmative steps so they don’t become one of the “unbefriended.” They are, however, struggling to find acceptable choices. ***So far solo seniors with “capacity” and who wish to be proactive haven’t received much attention.***

Is it possible for solo seniors to be proactive? If so, how do they create a backup plan for themselves in view of an extended later life that will likely include some health challenges? What resources are and should be available to craft that plan and at what point do such

resources need to kick in? Where are the gaps in the current Infrastructure? Who and how will those gaps get filled?

The purpose of this paper is to take a first step in exploring these and other questions. The intent is not to provide definitive answers, but to offer a big picture view of the key factors, questions and how they intersect. Ideally, compiling salient research and ideas in one document will help jumpstart further work and thinking about how to better support solo seniors and others as they navigate the end of life landscape. Every day thousands of individuals celebrate their 65th birthday—the traditional demarcation of 'seniorhood.' There is no time to waste.

The Current Landscape

Solo Seniors - A Snapshot

The pool of solo seniors is a fluid one, making it difficult to count or clearly define its members at any one time. In researching the topic, no verifiable statistics about solo seniors or efforts to gather such data were found. The most credible information about the potential size of the pool is the US Census data referenced previously. To better illuminate this group for the purposes of this paper, several informal methods were used to obtain a snapshot of people who self-identify as solo seniors or elder orphans. Personal anecdotes and sample phone interviews were collected in the St. Paul/Minneapolis area during the summer and fall of 2015. In addition, between January and July 2016, anecdotal information was obtained from a private Facebook group whose 800+ members identify as solo seniors. This preliminary information offers useful insights into needs, preferences, and circumstances.

This informal research suggested that among the most common types of solo seniors are:

- Never married individuals with no children whose other family members [siblings, cousins) are physically distant;
- People who are single [never married, or as a result of divorce or the death of a spouse] without children and estranged from or not well connected to other family members;
- People with children, but who are estranged from them. (Reasons for estrangement include dysfunctional families and persons with mental illness or personality disorders whose families have abandoned them.);
- People with spouses/ partners, family, and/or friends who do not wish to burden such people with end-of-life decisions and tasks;
- People with children and/or family members and/or friends but who have concerns about the ability of those children /family members/friends to make difficult medical decisions and manage end of life tasks;
- People who have close personal friends, but whose friends are close in age or older;
- People who have outlived immediate friends and family.

One specific population group whose members are likely to fit into one or more of the above descriptions is the LGBT community. Researcher Brian de Vries has studied such older adults in the context of end-of-life-decision making. According to de Vries "...LGBT older persons, especially gay men, disproportionately reach the very later years without partners, without children, without traditional families—i.e. without those people typically called upon to provide care or to participate in end-of-life preparations."⁹ Findings from this work are likely to be relevant across the entire spectrum of solo seniors.

This is not an exhaustive list of types; other permutations are both possible and likely. Differences in race and ethnicity are among the factors that may influence choices,

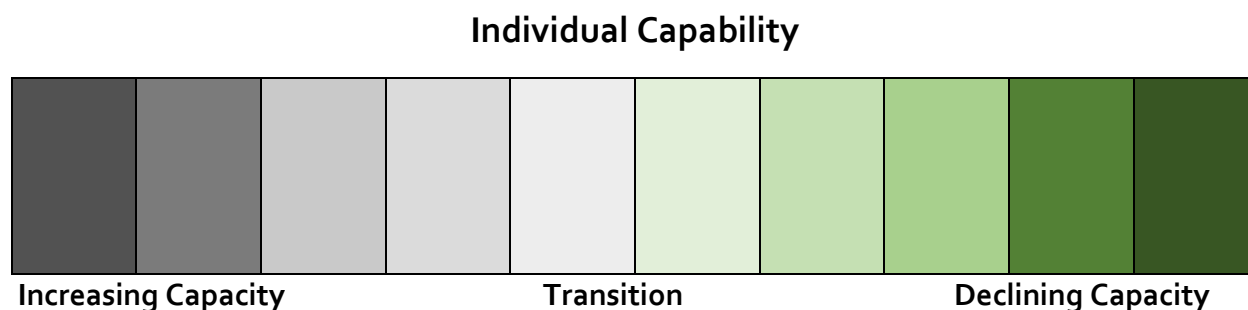
preferences, and traditions relative to later life. Solo seniors who live in rural areas may be especially challenged to find solutions.

The list is, however, illustrative of the fact that the solo path is often as much about personal choice as circumstances beyond the individual's control. Generational character is an often missed element in discussions about later life. The older adults who are currently facing end-of-life decisions are mostly members of what some have labeled "The Silent Generation." Noted for their hard work and respect for institutions, these individuals earned the label for their penchant to "say nothing" and "go along." In contrast, the older adults of today and the near future largely consist members of the Baby Boom cohort. A 2007 book, *Generation Ageless*, documented how prevailing social, economic, and technological dynamics shaped the world view of those born between 1946 and 1964. "The notion that Boomers are going to keep at it no matter how old they get runs counter to our expectation of old people. Yet this is the reality for aging Boomers. They have no intention of giving up on life's possibilities."¹⁰

Health Care Surrogates – Current Status

Nearly everyone experiences the path from birth through death as a series of incremental changes. Research has shown that when we enter the world, we are not fully "cooked." We lack teeth, can't sit up by ourselves, and it will take almost two decades for our brains to be completely developed. As time goes on, though, things change and usually improve, until some turning point is reached. Change then continues, but generally in the direction of decline—physically and mentally (Figure 1).

Figure 1. Life Continuum



Historically the model for later life support and decision making can best be described as a pyramid. Older adults have relied on several layers of subsequent generations to help them through to the end of the continuum (Figure 2a). As noted earlier, new demographic patterns are causing the pyramid to flip, so there are increasing numbers of seniors at the top, fewer younger people at the bottom (Figure 2b). However desirable the traditional model, the reality

is that a growing portion of the population will reach the “declining capacity” end without a pyramid to prop them up.

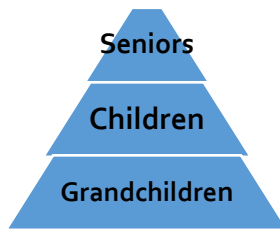


Figure 2a. Traditional Family Support Model

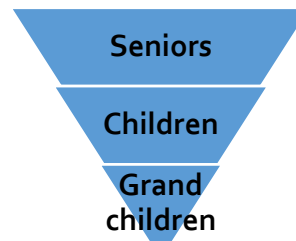


Figure 2b. Long-Term Demographic Change

The default solution for people who have no late life support system and plan has typically been government intervention, whereby one or more surrogates are appointed to handle financial matters (conservator) and/or personal matters (guardians). Today every state has adopted laws authorizing this kind of approach, though specifics vary across the country. For example, California, has adopted rigorous policies, including a requirement that guardians and conservators be licensed. States, such as Illinois, Indiana, Kentucky and New Jersey require guardians to be bonded while Alaska, Arizona, and Missouri do not.¹¹

On the surface, this two-pronged strategy might seem sufficient, but flaws are beginning to appear. For everyone, the “transition” period is getting longer and medical decision making more complex. Added to that is the growing consensus by elder care professionals and others that for people without family or friends, government intervention should be a last resort option because it involves taking away individual choices and rights. The National Guardianship Association has even adopted a formal position stating “Guardianship should be utilized only when lesser restrictive supports are not available.”¹²

Fortunately, over the last thirty years, important steps have been taken to formulate some of those less restrictive options. Among the most significant developments have been the following.

- **National Legislation** – As a result of two highly visible end-of-life court cases (Karen Quinlan, Nancy Cruzan), the US Congress passed the Patient Self Determination Act in 1990, delineating the right of adult individuals to craft written instructions regarding medical care (advance directives) under relevant state law.¹³
- **Expansion of Advance Care Planning** - A wide range of organizations (medical, nonprofit, faith communities) are encouraging and facilitating the development of Advance Care Directives and Provider Orders for Life-Sustaining Treatment (POLST – written orders for clear, actionable, transferable orders for their post-capacity

treatment¹⁴).

- **Improved State Laws**—Some 44 states have “default surrogate consent” laws for situations where a medical decision is necessary but where no Advance Directive exists. These laws provide a hierarchy of family decision-makers that medical providers can consult to make medical decisions on someone’s behalf. Over 20 of these statutes now specify that a “close friend” familiar with the person’s values can make the decision if family options don’t exist.¹⁵

Though the foundation is improving--to reiterate--there is still a big hole to be filled in for solo seniors—and even others. The above developments provide better tools for conveying end-of-life preferences to doctors and proxies. They also help the medical community to clarify who to consult in the *absence* of clear instructions. What none of the above resolve is the “who” question when a solo senior cannot or *chooses* not to rely on family and friends. It isn’t enough to have a set of documents with instructions and preferences. There must be a person or persons to fulfill the various roles that may come into play. These roles may include serving as an advocate, investigator, coordinator, protector, planner, decision enforcer, as well as a decision maker.

In summary, the landscape is getting better, but there are still too many people who don’t know whose name to fill in on an Advance Directive form.

A Critical Role

What kind of person or persons should be plugged into an end-of-life plan? A number of organizations have created “user friendly” written materials to help with the selection process. A good example is a section of the National Hospice and Palliative Care Organization’s web site entitled “Selecting Your Health Care Agent.” It suggests that a health care surrogate should be someone who “knows you well, is calm in a crisis, and is not afraid to ask questions...” among other abilities.¹⁶

As part of the sample interviews for this paper, solo seniors were asked to delineate the qualities, skills, abilities, etc., they would seek in a health care proxy. Some common expectations offered were that the individual would:

- be ethical
- be able to figure things out and ask questions
- have good communication skills
- be an advocate
- be objective
- be knowledgeable about death with dignity
- not impose own personal beliefs, values on decisions

Above all, the interviewees wanted someone who would be able to implement the written instructions in their Advance Care Directives, no matter how difficult the circumstances. As one interviewee put it: “What I really want is a pit bull.”

Interviewees also revealed expectations about how they would interact with a health care proxy. They talked about having in depth discussions about their health and preferences and having regular contact, either in person or by phone. In short, they expected to develop a relationship and to build trust.

This informal assessment is consistent with formal research about end-of-life goals and expectations. A systematic review of 40 studies conducted by Brenna Kelly, Annette Rid, and David Wendler, suggests that individuals have three primary goals with respect to how treatment decisions are made for them: to have close family members make treatment decisions, typically in consultation with the individual’s doctors; to be treated consistently with their own preferences and values; and, to minimize the burden on their families.¹⁷

There seems to be a lot of agreement that communication is an essential ingredient in creating (and ultimately implementing) a plan for later life. However, idealistic views and reality are not necessarily in alignment for solo seniors and others, according to one key player in the movement supporting end-of-life-planning. The Conversation Project prominently displays the following statistics on its web site:

90% say talking with family and friends about end-of-life care is important
27% have done it

82% say it is important to put wishes in writing
23% have done it¹⁸

Finding the “right” individual(s) to serve in a proxy role is only part of the equation; an effective process is equally important.

Pathways

How can people identify someone to serve as a health care proxy? There seem to be four basic pathways, as shown in Figure 3: Personal Relationships, Constructed Relationships, Professional Relationships, and Legally Directed Relationships. Each will be discussed more fully.

Figure 3. Basic Pathways to Health Care Proxies

Personal Relationships	Constructed Relationships	Professional Relationships	Legally Directed Relationships
Family members and close personal friends	Relationships created through “affinity” organizations	Relationships with paid professionals	Guardians and conservators acquired through a legal process
Traditional pathway	Emerging pathway	Emerging pathway	Traditional “last resort” pathway

Personal Relationships

As noted earlier, family and friends have long been the bedrock of later life support and will continue to be the proxies of choice for a large share of the population. Having a personal connection, through blood and/or history, however, does not automatically translate into either ability or effective judgement. Bioethicists have said that an effective surrogate is one who can accurately communicate and make the same decisions the patient would have made if he or she were able to do so (the substitute judgement standard). Research has shown that “...in practice, however, surrogates often do not choose the treatments dying persons would have chosen and differed in about 32% of the time.”¹⁹

A 2013 study by Sara M Moorman and Megumi Inoue of Boston College included a summary of recent research on family members as health care surrogates. Noteworthy findings are that “...spouses may often fail at substituted judgement: Random guesses are just as likely as surrogate choices to match ...preferences.....spouses are more likely than adult children to make a correct substituted judgement.”²⁰

This is not to imply that all of those in the Personal Relationships category are bad or problematic surrogate options. The above data do underscore, however, the difficulties inherent in making medical decisions for another, no matter what the relationship. It suggests that those who are part of the traditional pyramid may, in fact, require some shoring up of their own.

Constructed Relationships

An emerging pathway for finding late life helpers and proxies can best be described as that of Constructed Relationships. In short, these are relationships that people create for themselves or others put together for them that do not involve the traditional governmental action. It is a natural fit for those Boomers who find themselves in the solo senior category. In the book *Generation Ageless*, authors J Walker Smith and Ann Clurman point out that Baby Boomers are now reaching a point where they are reviving an interest in connecting with one another, particularly around lifestyle interests. This is giving them the opportunity to interact with and get to know others with whom they might not have had contact in the past.²¹

Evidence of this trend is visible in the Facebook group mentioned earlier. One of the most frequent topics of discussion and sharing has been the issue of cooperative living arrangements. There is considerable interest in exploring options for collaborating with other solo seniors to craft solutions other than the traditional age-segregated senior housing. Examples of just such living arrangements are expanding throughout the United States, along with relevant resources. These are described in Beth Baker's 2014 book, *With a Little Help From Our Friends*. Among the ideas are housing cooperatives, shared housing [the "Golden Girls" home], the "Village" model, and Naturally Occurring Retirement Communities (NORCs).

The Village model stands out as having much potential for constructing late-life support. Here, typically a group of people living in close proximity (though not necessarily in the same physical dwelling) form a nonprofit organization. The nonprofit provides a vehicle for contracting with providers of various kinds of services to meet the needs of participants. It might be an avenue for solo seniors to acquire and share the costs of care managers and health care proxies.

Whatever the specific model, the arena of collaborative living arrangements is relevant to health care surrogates. The kinds of conversations—and relationships--required to create a cohesive living community are the same as those needed in last chapter of life discussions. They involve enunciating clear expectations, exploration of values, and building of trust. This kind of community building may well be a pathway to individuals who can play the critical proxy role.

Another example of a constructed relationship is that created through a more familiar kind of "affinity" group—a faith or spiritual organization. The faith community has long played an important role in helping those in need and in addressing community problems. Faith

organizations all across the United States are now taking on end-of-life conversations. In Minnesota, for example, between 2012 and 2015 the Minnesota Council of Churches implemented the “Graceful Journey” program with some 90 churches and 11 other organizations. Some of these and other Twin Cities area churches have enlisted volunteers to help their fellow elderly congregation members with various tasks, including serving as decision surrogates.²² With further development, this could be a productive pathway for some solo seniors.

Still another example of Constructed Relationships was revealed through the anecdotal information gathered for this paper. Some solo seniors are taking the initiative to create groups to talk about and support each other around end-of-life issues, including serving as a health care proxy for one another. Common tools for making these connections are “Meet-Up” groups, Facebook, and other online forums. This approach merits further investigation to see whether specific models could be created for others to follow.

A final kind of constructed relationship is one created under the umbrella of a volunteer initiative. Two recent examples were specifically aimed at seniors who already could be deemed unbefriended elderly or were at risk of doing so. From mid-2008 to mid-2010, Volunteers of America-MN recruited volunteers to assist targeted older adults in locating a family member or friend to serve as their health care proxy and also to complete an Advance Care Directive. And, in 2010, in Indiana, the Wishard Voluntary Advocates program, began implementing a (non-governmental) guardianship program using trained, supervised volunteers who were either medical or law students. The Wishard Program is continuing, but the VOA initiative was discontinued because it was deemed too resource intensive.

Professional Relationships

Of the four pathways identified, the area of Professional Relationships is the one that merits priority attention. Numerous writings have documented the difficult and complex health scenarios that are possible for older adults. Furthermore, it is clear from the sample interviews, that solo seniors have expectations that surrogates will be competent and able to perform under pressure. In concert with these realities, some have begun to call for the expanded development of professional health care proxies. In 2012, authors Berman, Weiss, Howe and Fleming, made the case for a *health care fiduciary*. “A health fiduciary would be a new type of professional certified to act as surrogate decision-maker for individuals who become unable to make decisions for themselves.”²³ The health care fiduciary role could potentially be operationalized in different kinds of settings, including both for profit and nonprofit organizations.

Having the ability to select and retain a professional is likely to appeal to Boomers who, as has been stated, have a natural inclination to want to be in charge of their own destinies as long as possible. There are many associated questions to be explored and addressed, though, including the following. How will these professionals be created? What credentials should

they have? Where will they be located? How can the role be performed without creating conflict of interest problems? What kind of, if any, mechanisms should be created to monitor accountability? What are the associated costs, and how will people pay these costs?

The last question is not a trivial one. According to the National Institute on Retirement Security, “the median retirement account balance is...\$12,000 for near retirement households.”²⁴ Similarly, the National Council on Aging has found that some 47% of single Social Security recipients aged 65+ depend on Social Security for 90% or more of their income.²⁵ Clearly some creative thinking will be essential to find funding solutions for health care proxies and other late life medical expenses.

The marketplace is beginning to surface answers to some of these questions. In various places throughout the United States, businesses are springing up that offer professional health care fiduciary services. Two examples are the Decades group in Albuquerque, New Mexico and LifeBridge Solutions, LLC based in Beverly Hills, California. They advertise various supportive and substitute decision services for a fee. Additionally, there are solo practitioners who can be retained as a health care proxy. A drawback to the single-person solution was voiced in a personal interview with one such individual during the research process. The business owner planned to retire and was deliberating over what to do with certain clients. In an effort to be proactive, the clients had contracted for services to be used at some unknown point in the future. Ironically, it now appears that the clients will outlive the business. It may be that larger firms may be better able to serve solo seniors over the long term.

Individuals who are experienced and qualified to serve as Guardians under state law are another “professional” option for solo seniors. A quick search of a few existing Guardian lists indicated that some people who work as Guardians will and do serve as health care proxies outside of a court mandated process. On a related note, there are some nonprofit organizations that run Guardianship programs pursuant to state law. A representative of one such program indicated that the organization frequently gets calls from individuals who are in need of a health care surrogate (again, to be provided outside of the court process). According to the representative, the agency would love to be able to respond to these requests but a change in state law might be needed before it could do so. With more investigation and work on any potential roadblocks, nonprofit agencies like this one might be part of a long term solution.

The professional health care fiduciary is a potential solution worthy of more effort, but not only to address the needs of solo seniors. Clearly the surrogates acquired through both the Personal Relationships and the Constructed Relationships pathways may need and desire some kind of backup. It could be very helpful for them to have a credentialed and experienced person to help them through the toughest issues.

Legally Directed Relationships

A few of the key concerns about the fourth and default pathway have already been mentioned. On top of the critically important matter of taking away rights is the fact that court supervised Guardianships are an expensive option. The VOA-MN pilot project mentioned earlier, used an estimated initial cost of from \$ 3,000 to \$10,000 in attorney's fee to set up a Guardianship.²⁶ Add to that the ongoing costs of performing the day to day Guardianship tasks which can be significant, particularly if the older adult requires services over several years. If the older adult has assets, then those assets will be used to cover the costs. In the event assets are limited or nonexistent, local government assumes the costs.

Reliable and consistent data about the number of Guardianships that are initiated in the United States each year are lacking. The best estimate available comes from a 2010 report developed for the Center for Elders and The Courts that used online survey methodology. Three of the most reliable data sets for the year 2008 came from California (39,900 cases), Minnesota (28,012), and New York (17,518). Consider how those totals might change in view of the number of solo seniors projected over the next several decades. And, even more important, consider the potential public liability if the government must pick up the tab. It is in everyone's best interest to help solo seniors to be proactive and find better alternatives.

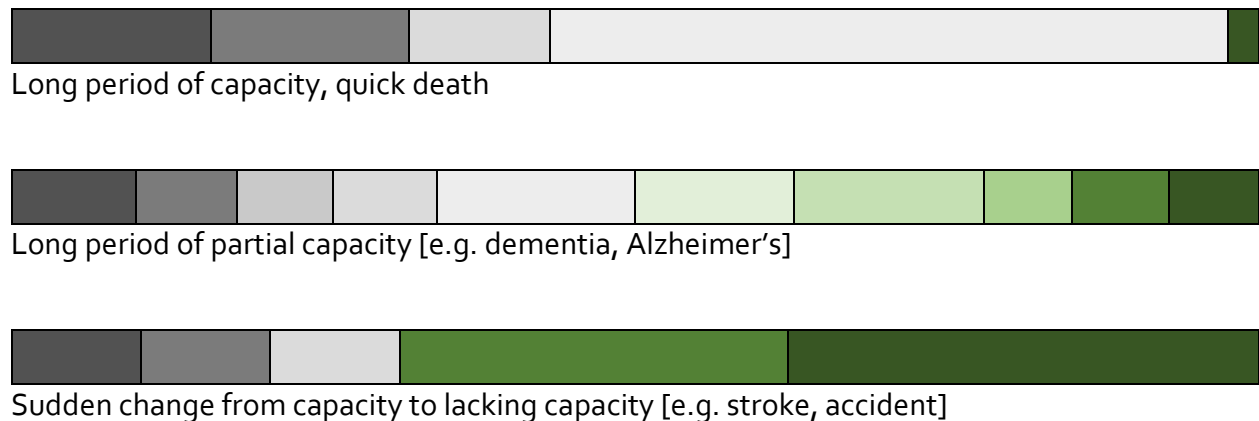
Big Decisions and Small Decisions

Supported Decision Making

The evolution of the Advance Care Directive concept has been significant on many levels. Having such a tool and accompanying legal framework has stimulated many discussions that have helped people to think about the unthinkable. But however useful these discussions have been, the dominant theme has been on the “big” decisions that might show up near the very end of the life. Easily obscured is the bittersweet reality of a longer lifespan combined with chronic conditions that also demands medical decision making.

According to the National Academy on an Aging Society, chronic conditions are a leading cause of illness, death, and disability in the United States, especially for older adults.²⁷ Adding complexity is the possibility that solo seniors and others might spend an unknown number of years with declining or lack of capacity due to Alzheimer’s disease, other forms of dementia, or stroke. As was illustrated in Figure 1, a typical life continuum for current and future older adults will likely include a transition period, but the timing and length of the transition will vary, depending on factors such as genetics and lifestyle, illustrated in Figure 4.

Figure 4. Alternative Life Scenarios



Geriatrician Dr. Joanne Lynn of the Altarum Institute frames this issue in a similar way. She points out the three most common ways that old people die: many years of good health followed by a few weeks or months of a steep decline (e.g. cancer deaths), alternating periods of severe illness with relative stability (e.g. death from heart or lung disease), and death following extended frailty and cognitive impairment (e.g. Alzheimer’s disease).²⁸

Medical decision making will undoubtedly be a part of any scenario with a long transition period, but most such decisions can likely be characterized as “small” rather than “big.” Examples of small medical decisions are whether a doctor’s visit is needed to address a persistent cough, when to seek the advice of a specialist, or whether to undergo minor surgery.

These are in contrast to the big decisions about terminating a treatment, withholding food or water, or using an experimental drug. Though some Advance Care Directive forms and associated planning processes do touch on the possibility of Alzheimer's disease, the need for making "small" medical decisions over a long period of time has not received much attention. The *Dying in America* study referenced earlier suggested that some 70% of older adults facing treatment decisions require assistance in making those decisions. For solo seniors, this is an especially critical issue.

The pyramid model is currently the operative one for transition period care and decision making. A 2015 AARP report indicated that in 2013 some 40 million family caregivers in the US provided an estimated 37 billion hours of care to an adult with limitations in daily activities.²⁹ The study did not specifically break out the proportion of those hours that were devoted to medical decision making. It did however acknowledge that selecting, coordinating, and supervising services were key roles in the mix.

In the absence or inability of family members, solo seniors will need a competent and willing individual to help them through the transition period. Here, it may be useful to consider the concept of "supported decision making." The term supported decision making is most often used in the context of those with intellectual or developmental disabilities. At its core is the notion that such individuals can and should be able to make personal decisions for themselves with appropriate support as needed. This idea is highly applicable to solo seniors. In fact, selecting someone to fill this role might well be a higher priority than selecting a health care proxy for the very end of life. It might well be that a person who starts as a decision supporter could evolve into a health care proxy. Care management and supported decision making certainly deserve a full discussion as part of the process of creating a backup plan for later life.

A Final Observation

Helping older adults to be in charge of their lives and reducing pressure on public resources are two solid reasons for paying more attention to solo seniors. There is, however, one more equally compelling reason: avoiding elder abuse. Solo seniors may be ripe targets for financial and medical scams of all kinds. In addition, those without medical decision supporters and/or proxies are at risk for the equally troubling form of abuse—self neglect. According to the National Center on Elder Abuse, "the elderly may be reluctant to report abuse themselves because of fear of retaliation, lack of physical and/or cognitive ability to report, or because they don't want to get the abuser in trouble."³⁰ Providing better systems and resources to support solo seniors will be essential to make sure they don't add to already troubling abuse statistics.

The Way Forward

The notion of “elder orphans” and issues associated with them has been around for nearly three decades. Related research in several disciplines is beginning to show up and the popular press is starting to focus on the ramifications of this growing sub-group of Baby Boomers. While improved public awareness is essential, it is not sufficient to address the challenges that solo seniors face when it comes to navigating later life. A more deliberate strategy and associated set of actions is essential if there is to be progress. Based on the research for this paper, that strategy and set of actions should include the following.

1. ***Better Data About Solo Seniors.***

Right now solo seniors are largely invisible, except for those who earn public attention because they are the most vulnerable—the so called “unbefriended elderly.” We need to expand understanding of this diverse and complex group, looking at living arrangements, income, overall health, age range, geographic locations, among other things to be better able to plan for and support them. Gathering and evaluating data using rigorous methodology is a key step.

2. ***Development of Professional Health Care Fiduciaries.***

Solo seniors who need assistance with financial matters have a number of support options, including daily money managers, attorneys, banks, and other kinds of financial professionals. There is a big gap in the resources available to help with health care management and decisions. Knowledgeable professionals need to come together to conceptualize and develop the health care fiduciary role. Such a dialogue should be interdisciplinary and focus on qualifications, training, and how to assure accountability, among other topics.

3. ***More Options for Financing Supported and Surrogate Health Care Decision Making.***

Part of the process of developing the health care fiduciary role should be tackling the thorny issue of how to pay for both supported and surrogate decision making. Private pay may be an option for some solo seniors, but other options such as health insurance, health savings accounts, and long term care insurance should also be evaluated. Everyone will be better served if there are choices.

4. ***An Expanded Set of Resources & Improved Accessibility of Existing Resources.***

Late life tasks and decision are challenging—for family members, friends, solo seniors, and others. Additional resources are needed, particularly for those who may wish to follow the “Constructed Relationships” pathway. Some possibilities: experiential training for non-professionals who agree to serve as health care surrogates; groups of people who have served as a health care proxy and who are available to mentor others taking on the role; an “Angie’s List” of non-profit and for profit organizations that have services geared toward solo seniors; resources and models for how to build community,

particularly with individuals from younger generations.

A companion effort should be making sure that people know about and can easily access good resources that already exist. (In the course of research for this paper, excellent materials were identified, that were buried in web sites not readily known to the average person.)

5. *Inventorying and Highlighting Best Practices.*

All across the United States there are governmental and non-profit agencies that have been attending to the needs of the elderly for a long time. Some of them have developed effective practices and procedures for working with solo seniors. We need to surface existing best practices and share these with organizations that might be in a position to serve solo seniors who have not reached the “unbefriended” stage. Similarly, we need to encourage all agencies who work with the elderly to better understand the solo senior population and modify existing systems to accommodate future needs.

6. *An Improved Model for Late Life Planning.*

Finally, it is important to develop a different model for a late life “backup plan.” The pyramid is being threatened not just by changing demographics, but also by a major flaw in the design. It is built around the assumption that one or two people have the ability and stamina to play multiple and difficult roles to support elders.. The Family Caregiver Alliance, AARP, and others have amply documented the extreme stresses that spouses, daughters, sons, and friends experience when they become advocates, investigators, decision makers, task handlers, and care managers for older adults. It does not make sense, therefore, for solo seniors to endeavor to replicate the pyramid using people other than family. A change in overall approach is needed.

The reality for all is that life circumstances change over time. Instead of trying to find a substitute family member who will be available to meet all needs over many years, solo seniors must work in harmony with the reality of longer lifespan. A better approach might be to reframe the issue as “quality of life” planning and approach it as a series of increments. For example, the solo senior could ask “what kind of life do I want in the short-term and what kind of support system do I need for the next five years to achieve that?” The individual might not need a care manager in that time frame, but might need an emergency contact and someone to accompany them to a colonoscopy appointment. An Advanced Care Directive would serve as a foundation. At the end of the five-year period, circumstances might have changed, so some parts of the plan might require modification [e.g. a different person) and other resources added.

It is extremely difficult for people to accurately predict needs and resources in the long-term; far easier to think about what is important and available in the near future. It also makes more sense for solo seniors to separate the roles and consider which ones are most needed at a particular point in time and who might be best suited to each role. The “one size fits all” approach inherent in the traditional pyramid probably isn’t the best one for solo seniors. The alternate model, is more akin to a handful of Legos™ than a pyramid. It is a set of flexible building blocks interconnected with one another.

Some solo seniors are already experimenting with this model by putting together groups to share the tasks and provide support. The Legos™ approach is very consistent with the recommendations of attorneys and organizations that facilitate end-of-life planning. A common message is to periodically revisit decisions captured in wills, Power of Attorney documents, and Advance Care Directives. It is easy to file away the documents, though, once the difficult work is complete. Solo seniors and others will be better served if the more modular approach is strongly reinforced.

Conclusion

We have long recognized that people come into this world lacking full capacity and requiring support. In response, we have created an infrastructure to shore up young people until they can fend for themselves. That infrastructure is made up of supportive and substitute decision makers in the form of parents, grandparents, teachers, and coaches, along with laws that, for example, set a minimum age for driving a car or consuming alcoholic beverages. The same kind of infrastructure has not yet been fully crafted for years when capacity declines. It isn’t enough to concentrate on the far end of the life continuum, when people are at their most vulnerable. We must also create resources and systems that allow people to be proactive and take charge of their lives for as long as possible, especially when it comes to health care decisions.

The “last chapter” infrastructure cannot be based exclusively on the model of traditional family support. A growing portion of the population—one that is invisible to many—is composed of those who cannot or choose not to rely on family. This segment is not a temporary aberration; subsequent generations are exhibiting the same declining fertility rates and varied living choices as the Baby Boom Generation. It is time for these solo seniors to become more visible and the associated infrastructure gaps to be addressed. Doing so will have tangible payoffs for other older adults and their families as well.

End Notes

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Self Identified "Solo Seniors"

Volunteers of America, Minnesota

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