

# **Care Planning Across the Long-Term Care Continuum: Fundamentals**

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## **Elder Law: A Shifting Paradigm**

Elder Law envisions itself as a holistic practice, focusing on the *living* needs of older persons. The NAELA website describes it as follows: “Elder Law attorneys focus on the legal needs of the elderly, and work with a variety of legal tools and techniques to meet the goals and objectives of the older client. Under this holistic approach, the elder law practitioner handles general estate planning issues and counsels clients about planning for incapacity with alternative decision making documents. [They] also assist the client in planning for possible long-term care needs, including nursing home care. Locating the appropriate type of care, coordinating private and public resources to finance the cost of care, and working to ensure the client's right to quality care are all part of the elder law practice.”<sup>1</sup>

Notwithstanding aspirational beginnings, Elder law is perceived as having devolved into a Medicaid asset protection practice that is derided in the community.<sup>2</sup> The perception is that Elder Law has given up on living clients; now it frequently serves their heirs. Whether the reputation is deserved or not, it is difficult to deny that the public thinks of “Elder Law Attorneys” not as practitioners who help living Elders navigate the long-term care maze, but as the people who save the money from the nursing home.

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<sup>1</sup> NAELA, What is Elder Law?, <http://www.naela.org/public/whatisEL.htm>.

<sup>2</sup> See Medicaid Planning Quotes, at [http://www.centerltc.com/medicaid\\_planning\\_quotes.htm](http://www.centerltc.com/medicaid_planning_quotes.htm).

Interesting, by allowing this to take place, we have narrowed our market of potential clients. Since Medicaid has an institutional bias, Medicaid planning focuses only on the nursing home admission and on estate recovery. In other words, we have educated the public to believe that we limit our planning to the far end of the long-term care continuum and are, in effect, giving up on the rest. Instead, of helping living elders, we offer to save their money. This tendency to view Elder Law as being synonymous with Medicaid planning is untenable and is inconsistent with what elders want from the long-term care system. It is time for us to engage our clients in conversations about the rest of the long-term care continuum.<sup>3</sup>

## **Morbidity and disability rates among the Elderly are declining**

Recent data suggests that market factors will force practitioners to re-think how Elder Law is practiced. Previously, many Elder Law Attorneys presumed that an aging America meant there will be more Medicaid planning clients. This presumption is not necessarily true; it presumes an expansion of morbidity.<sup>4</sup> If

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<sup>3</sup> An article describing the “real purpose” for hiring an Elder Law Attorney, which is to make sure loved ones are taken care of, appeared recently in the NAELA News. See R. Nagaich, Medicaid Planning vs. Care Planning for the Incapacitated Client, 18 NAELA News 9 (2006).

<sup>4</sup> Three competing theories have emerged since 1977. The expansion of morbidity theory asserts that longer life will be associated with a prolonged period of morbidity and disability. The compression of morbidity theory asserts that the onset of chronic, irreversible illness will be delayed so that the period of infirmity will be compressed into a shorter period of time before

morbidity expands, then there would indeed be an increased demand on government benefits programs<sup>5</sup> and, possibly, in applications for Medicaid. However, recent data suggests that even as America ages, disability rates among the elderly are declining. The result of this decline likely means fewer nursing home admissions per capita and fewer per capita applications for nursing home Medicaid.

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*“The baby boom generation that reaches the age of 65 in 2011 will account for twice as many older adults in 2030 as there are today; however, if the demand for nursing homes continues to decline at just half the rate of the past 20 years, there will be only 320,000 more nursing home residents among the “oldest old” instead of 830,000 more.”<sup>6</sup>*

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death. An intermediate scenario, dynamic equilibrium, predicts an increase of moderate or light morbidity and disability as medical advances delay the onset and reduce the incidence of chronic diseases and increase the survival and improve the health of the chronically ill. See L. Cai & J. Lubitz, *Compression of Disability for Older Americans: 1992-2002* (Draft March 22, 2005), at <http://paa2005.princeton.edu/download.aspx?submissionId=51363>.

<sup>5</sup> “As the share of the population 65 and over climbs, federal spending on the elderly will absorb a larger and ultimately unsustainable share of the federal budget and economic resources. Federal spending for Medicaid, Medicare, and Social Security is expected to surge—nearly doubling by 2035—as people live longer and spend more time in retirement.” GAO, *Long-Term Care Financing: Growing Demand and Cost of Services are Straining Federal and State Budgets*, p.9 (April 27, 2005).

<sup>6</sup> *New Long Term Care Study Shows Dramatic Shift Away From Nursing Homes For ‘Oldest Old’* (Nov. 22, 2006), at <http://www.medicalnewstoday.com/medicalnews.php?newsid=57316>.

Further, a compression in morbidity will almost certainly reduce the length of time spent in a nursing home, as well as the perceived risk of impoverishment. For example, assuming one month of nursing home care costs \$7,500, then a one month reduction in the nursing home stay saves \$7,500. In point of fact, the average length of stay has declined as indicated in the table below. The reduction in the average nursing home length of stay from 1985 to 2004 translates into a 17% reduction in the funds at-risk to pay for care. If the fear of impoverishment is the driving force behind Medicaid planning, then perceived fear may be diminishing.

**Reduction in Amount at Risk**

	<i>Average Length of Stay</i>
1985	2.9 years
2004	2.4 years
	<i>Median Length of Stay</i>
1985	1.7 years
2004	1.3 years

*Source: Lewin Group, Nursing Home Use by Oldest Old Sharply Declines (November 21, 2006).*

The data suggests that the compression of morbidity hypothesis is winning out. This is attributed to various factors including better education among the elderly; socioeconomic shifts; changes in chronic disease and related treatments; trends in underlying physical, cognitive and sensory functioning; and environmental changes, particularly the growth in the use of assistive devices.<sup>7</sup> We can expect these trends to continue,

<sup>7</sup> See V. Freedman, *Late-Life Disability Trends, An Overview of the Current Evidence*, Appendix E in *Workshop on Disability in America: A New Look* (2006). Even so, progress made as a result of declining disability rates could be overwhelmed by the sheer number of persons reaching retirement. See GAO, *Long-Term Care Financing*, *supra*, p. 12.

in part, because there is a market in the United States for products and services that promote healthy living.

**Percentage of Population over 65 in Nursing Homes**

1985 4.2%  
2004 3.6%

**Percentage of Population over 85 in Nursing Homes**

1985 21.1%  
2004 13.9%

*Source: Lewin Group, Nursing Home Use by Oldest Old Sharply Declines (November 21, 2006).*

As important as declining disability, there is a lingering negative perception of nursing homes. Elders don't want to go to a nursing home so they are looking for other options. When surveyed, 29 percent of respondents indicated that they would rather die than go to a nursing home.<sup>8</sup> If we presume that Medicaid planning, and therefore nursing home care, is the only long-term care option for the elderly, or even the predominate one, then we are guilty of ageism<sup>9</sup> because other options exist. While the number of nursing home beds grew only 7% from 1990 to 2002, during the same period the number of residential care and assisted living beds grew by 97%.<sup>10</sup> Some analysts attribute

<sup>8</sup> *Id.*, at [http://www.medscape.com/viewarticle/434129\\_2](http://www.medscape.com/viewarticle/434129_2).

<sup>9</sup> "Ageism, that is, basing attitudes and treatment of a person on age, has long been recognized as a problem in the care of old people." R. Kane & R. Kane, *What Older People Want From Long-Term Care, and How They Can Get It*, 20 *Health Affairs* 114-127 (2001), available at [http://www.medscape.com/viewarticle/434129\\_1](http://www.medscape.com/viewarticle/434129_1).

<sup>10</sup> Harrington et al, *Trends in the Supply of Long-Term Care Facilities and Beds in the United States*, 24 *J. Applied Gerontology* 265, 269-271 (August 2005). In 1990 there were

this growth "as a response to consumer demand for residential care and assisted living organizations that emphasize privacy, independence, choice and autonomy, and flexibility in the amount and type of services delivered."<sup>11</sup> Other factors offered to explain the growth in this segment of the long-term care market include entry of chains such as Hyatt and Marriott into the market, a blurring of the lines between residential care and nursing home care, and changing reimbursement policies. Recent statistics concerning where elders live appear in the following table.

**Percentage of Medicare enrollees age 65 and over residing in selected residential settings, by age group, 2003**

Age	Community	Community Housing with Services	Long-term care facility
67-74	98	1	1
75-84	93	3	5
85+	75	8	17

*Source: Indicator 36: Residential Services, Older Americans Update 2006: Key Indicators of Well-Being, <http://www.agingstats.gov/update2006/default.htm>.*

**The Chronic Care Model**

A reduction in disability rates, coupled with a decline in nursing home admissions, does not mean that elders are without needs. Elders who have difficulty "getting through the day" may not be disabled, but they may have one

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519,905 residential care beds in the United States, while in 2002, there were 1,026,397. The authors caution that their report covers licensed beds and growth in the number of residential care and assisted living facility beds may be, in part, due to conversions of unlicensed beds to licensed beds.

<sup>11</sup> *Id.*, at 279, citing Mollica, R. L. (2002). *State assisted living policy 2002*. Portland, ME: National Academy for State Health Policy.

or more chronic conditions.<sup>12</sup> Planning along the entire elder care continuum begins with an understanding of the chronic care model for the delivery of health care. By this, we do not mean simply knowing that various housing options exist; instead we mean finding, getting and paying for good care with a real understanding of what patients struggle with on a day-in-day-out basis.

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The number of persons in the chronic care model is vast. “Almost half of all Americans, or 133 million people, live with a chronic condition. The number of Americans suffering from chronic disease is projected to increase by more than one percent per year by 2030, resulting in an estimated chronically ill population of 171 million.”<sup>13</sup>

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So what is the chronic care model for the delivery of health care? It was developed by staff working at the MacColl Institute for Healthcare Innovation and “identifies the essential elements of a health care system that encourages high-quality chronic disease care.”<sup>14</sup> The model, graphically, depicted on the internet, has the following elements: the community, the health system, self-management support, delivery system design, decision support and clinical

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<sup>12</sup> “The average 75-year-old suffers from three chronic conditions and takes five prescription medications.” Merck Institute of Aging & Health and the CDC, *The State of Aging and Health in America 2004*, Executive Summary, p. 1, at [http://www.cdc.gov/aging/pdf/State\\_of\\_Aging\\_and\\_Health\\_in\\_America\\_2004.pdf](http://www.cdc.gov/aging/pdf/State_of_Aging_and_Health_in_America_2004.pdf).

<sup>13</sup> <http://www.improvingchroniccare.org/change/index.html>.

<sup>14</sup> <http://www.improvingchroniccare.org/change/model/components.html>.

information systems.<sup>15</sup> Ultimately, the model envisions productive interactions taking place between “informed, activated patients” and “prepared, proactive practice teams.” How these interactions take place is where the life care planning lawyer enters the scene.

According to Dr. Ed Wagner, developer of the chronic care model, “[w]hen properly applied to well-informed patients, newer treatments can lead to major reductions in suffering and avoid complications, including death.”<sup>16</sup> Even so, in an on-line lecture, Dr. Wagner said the model suffers from several problems, the chief one being a lack of informed, activated patients.<sup>17</sup> Where do activated patients come from and how do they get informed? Conversely, how do informed patients get activated? One answer is through education. Patients need to understand the long-term care continuum and how to interact with prepared proactive practice teams. Lawyers and their care coordinators can fill this role.<sup>18</sup>

A second problem with the model is that health care financing is largely “stuck” in a third-party payor model. Financing is usually done on a fee for service basis that is linked to a diagnosis code. The

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<sup>15</sup> *Id.*

<sup>16</sup> RAM Leadership Group, *Resources: Leadership Guide, Section 16.1 – Chronic Care*, [http://www.ramcampaign.org/pages/RAMLeadershipGuide-Campaign\\_Issues\\_Chronic-Care.htm](http://www.ramcampaign.org/pages/RAMLeadershipGuide-Campaign_Issues_Chronic-Care.htm).

<sup>17</sup> The entire series is available at <http://www.researchchannel.org/prog/displayseries.aspx?fid=804>.

<sup>18</sup> “Caring for an incapacitated elder is not intuitive. In fact, unless a family member has a professional background in medicine or long-term care advocacy, most families do not know the questions to ask and find themselves totally dependant on the system to guide them through the process.” Nagaic, *supra*, p. 9-10.

current model assumes a face-to-face contact between the patient and the health care provider.<sup>19</sup> Good chronic care management, on the other hand, typically takes place between visits.

A third problem, less talked about by the health care community, but apparent to lawyers, is accountability. The chronic care model, like the acute care model, envisions relationships, but frequently health care providers feel more accountable to third-party financiers than to their patient. "The market model ... sets up a competitive, almost adversarial, relationship between patients and providers."<sup>20</sup> In this climate, one rightly asks "who stands with the patient?" Who will press for all of the options available, and not just those paid for by Medicare, Medicaid or insurance? As recent surveys show, health care providers don't always give patients the full range of options; sometimes infuse their own views into the care plan.<sup>21</sup>

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<sup>19</sup> J. Lemieux, *Improving Chronic Care in Medicare*, prepared statement for Senate Special Committee on Aging's Forum on Disease Management in Medicare (Nov. 4, 2003), at [http://www.ppionline.org/ppi\\_ci.cfm?knlgAreaID=111&subsecID=139&contentID=252156](http://www.ppionline.org/ppi_ci.cfm?knlgAreaID=111&subsecID=139&contentID=252156).

<sup>20</sup> D. Stone, *Shopping for Long-Term Care*, 23 *Health Affairs* 191, 196 (2004).

<sup>21</sup> F. Curlin, et al., *Religion, Conscience and Controversial Clinical Practices*, *N Engl J Med* 2007;356:593-600. 1144 of 1820 physicians responded to a survey where doctors were asked to think about their ethical rights and obligations when conflicts emerge in clinical practice. The study concluded that "[m]any physicians do not consider themselves obligated to disclose information about or refer patients for legal but morally controversial procedures." Even more provocative are views expressed in the book *Money-Driven Medicine*. There, the author indicates among other problems with the system, that unnecessary surgeries are often performed because they are profitable and that physician convenience may dictate a suggested

Quality care and accountability go hand in hand, but little is built into the system to encourage provider accountability to patients. Even the pay for performance model Medicare is currently piloting in 9 States fails at this since accountability is to Medicare, not the patient.<sup>22</sup> Holding others accountable, though, is what lawyers do for their clients.

## How We Plan Along the Continuum

Finding, getting and paying for good care is lawyer work. By way of explanation, health care is all about relationships and yet relationships are the fodder of law. The relationships may be direct or indirect. They may be based on contract or duty. Patients entering into health care relationships have access rights as well as the right to decline care. Existing or new relationships may trigger or create rights of reimbursement or obligations to pay. As relationships continue, parties to them may be held accountable to each other. And, as relationships continue, they should be re-evaluated on a regular basis.

In our office, we begin as do many practitioners by assessing our client's situation. We send potential clients a questionnaire soliciting information. However, the questions we ask are heavily weighted toward the client's current and prior health circumstances and their caregiver situation. When

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course of treatment. M. Mahar, *Money-Driven Medicine: The Real Reason Health Care Costs So Much* (Collins 2006).

<sup>22</sup> Medicare 'Pay for Performance' Initiatives, <http://www.cms.hhs.gov/apps/media/press/rel ease.asp?Counter=1343>.

clients bring this information to an initial meeting, an attorney and an Elder Care Coordinator (who has extensive experience in long-term care advocacy) meet with the client, initially discussing the elder's present circumstances and needs. Meetings of this sort frequently last for two hours. Frequently very little time is spent discussing finances, other than determining what resources are available to meet the client's needs.

In our initial meetings, we often describe the long-term care continuum visually (*See accompanying diagram*). This accomplishes several goals. First, it allows the persons in the meeting (often caregivers) to help us determine where the elder is on the continuum. Second, it allows the caregivers to see what changes could occur, and are likely to occur, if the elder's present needs are not met. Third, it helps us begin an education process designed to empower elders and caregivers to they can more effectively participate in the long-term care system.

Next, in our planning process, is a functional assessment of the elder's needs performed by our Elder Care Coordinator. Whenever possible, our care coordinators assess the elder where the elder is residing. Although the information supplied by the client is helpful, our experience is that clients often over estimate resources and under estimate needs.

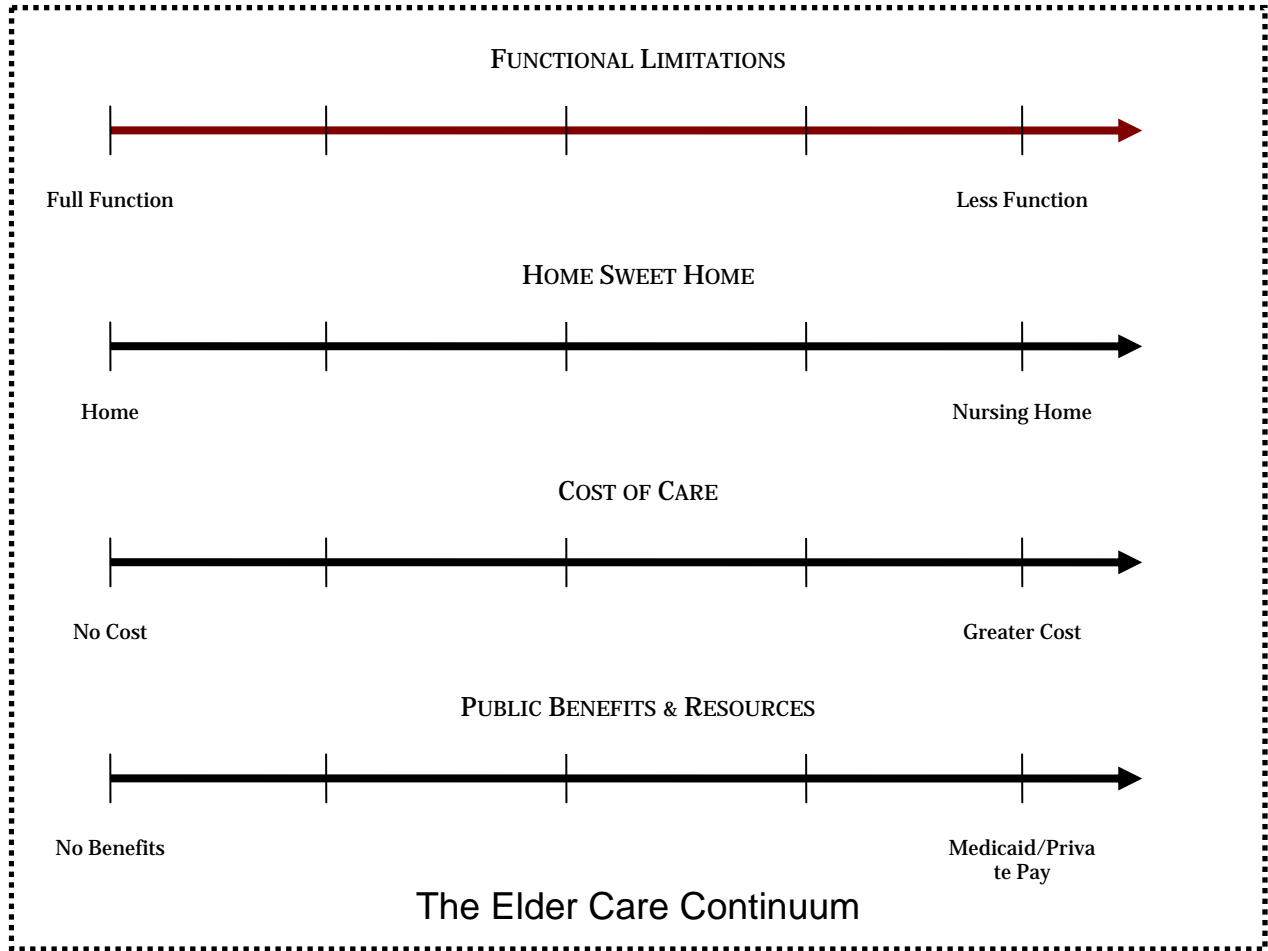
Our care coordinators report their findings to the attorney handling the case. The attorney prepares a life care plan that is then reviewed by the care coordinator. The life care plan includes health, financial, asset management, benefits, and estate planning components with each succeeding

component being driven by previous ones. In essence, the plan answers the question of how we are going to find, get and pay for good care.

After the plan is prepared that takes into account many of the factors described in the accompanying "issues list." Our care coordinators attend a second meeting with the client to review the functional assessment with the client. During that meeting, clients are given a copy of the plan, as well as supporting information. They are asked to read the plan before their next meeting in our office. During the third meeting, the attorney, the care coordinator and the client discuss planning options, including client preferences. The over-riding goal is to develop a safe strategy to help the elder hold his or her place on the care continuum or "to age in place." After the third meeting, all subsequent meetings respond to needs that arise in the client's life, often as a result of changes in condition or transitions.

Do we do Medicaid planning? Yes, but only to the extent that it supports the goals of the representation since the goal is to avoid nursing home placement. The goals as set out in our fee agreement are to (1) find, get and pay for good care for our clients; (2) to facilitate good health care decisions; (3) to increase income; (4) to facilitate good asset management; and (5) and to protect assets (i) for the elder, (ii) with surplus assets being protected for the heirs. We have found that this planning approach works in cases where there are no assets to protect, when the client can clearly afford to private pay, and in cases that are in-between.

# Elder Care Continuum



## Selected Issues in Life Care Planning

1. Is the Elder still in the work force?
  - a. Is the employment full-time or part-time?
  - b. How long can we reasonably expect the Elder to remain in the work force?
  - c. What factors would cause the Elder to continue to work (or retire)?
2. Is an adequate retirement plan in place?



- a. What are the Elder's goals during retirement?
  - b. Does the Elder have a financial plan?
    - i. Has the Elder prepared a budget?
    - ii. Does the Elder live within the budget?
  - c. What are the Elder's sources of income?
    - i. Social Security?
    - ii. Supplemental Security Income?
    - iii. Government Pensions?
    - iv. Private Pensions?
    - v. Individual Retirement Accounts?
      - 1. What are the income tax implications of using this asset?
    - vi. Annuities?
  - d. Are there options available to increase the Elder's income?
  - e. What assets are available to fund the Elder's retirement and care needs?
    - i. Personal residence?
      - 1. Is there a mortgage?
    - ii. Life Insurance (cash value)
    - iii. Investments?
    - iv. Savings accounts?
  - f. Is savings sufficient to fund any budget shortfalls through the Elder's remaining life expectancy?
  - g. Does the Elder have adequate insurance?
3. Are the Elder's relationships stable?
- a. Does the Elder have a stable marriage?
    - i. Is this a first marriage or a subsequent marriage?
    - ii. Are there children from a prior marriage who might have goals inconsistent with the best interests of the Elder couple?
  - b. Are there children and, if so, are they supportive?

- c. Are there any disabled persons who are supported by the Elder?
4. Does the Elder have the ability to direct his or her own retirement plan and health care plan?
    - a. Does the Elder have a plan and, if so, what is it?
    - b. Does the Elder have the ability to manage his or her own money?
    - c. Does the Elder have a General Durable Power of Attorney in place?
      - i. Are the agents capable of managing the Elder's assets?
      - ii. Are the agents close geographically and, if not, are there barriers to performance?
    - d. Does the Elder have Advanced Directives in place?
    - e. Has the Elder informed the Agent of his/her wishes regarding how assets are to be used and regarding health care preferences?
  5. What are the Elder's physical needs?
    - a. Are there any functional limitations?
      - i. Activities of daily living?
      - ii. Instrumental activities of daily living?
    - b. Does the Elder require any assistive devices?
      - i. Glasses
      - ii. Hearing aides
      - iii. Cane, walker, wheelchair
      - iv. Grab bars, rails, ramps
    - c. What caregiver support is in place?
    - d. Where are the danger zones?
  6. Is there an adequate plan in place to finance quality health care?
    - a. Is the Elder a Medicare recipient?
    - b. Does the Elder have a supplemental insurance policy?

- c. Does the Elder have a Medicare Part D policy or some other insurance program for prescription drugs?
- 7. Does the Elder have an Estate Plan?
  - a. Does the Elder have a Will?
  - b. Is the Will the Elder's primary device outlining testamentary disposition?