

Long-Term Care: “What Does Good Care Look Like?”

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Author's Note

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Many of the ideas in this paper came out of interviews with health care providers and with a physician, all of which donated their time to speak with the author. To preserve the confidentiality of those interviews, we do not name names, the information shared was invaluable and the author wishes to express appreciation.

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Foundations of Long-term Care

Getting and being "old" is a relatively new phenomenon. As recently as 1900, life expectancy at birth in the United States was 47. Now, it is 77.9 years.¹ During this same time period, the elder population grew rapidly, from 3.1 million in 1900 to 35 million in 2000.² As a nation, and as a culture, we are still coming to grips with the ramifications of long life, particularly as we prepare for an age wave predicted to double the elder population by 2030. Here, our focus is on those elders need long-term care. About eighty percent of elders have at least one chronic health condition and fifty percent have

¹ http://en.wikipedia.org/wiki/Life_expectancy.

² 65+ in the United States: 2005, p.1 (U.S. Census Bureau December 2005).

at least two. Arthritis, hypertension, heart disease, diabetes and respiratory disorders are some of the leading causes of functional limitation among the elderly.³

Current health care often fails to meet the needs of chronically ill people. Treatment regimens for chronic illness often do not conform to evidence-based guidelines. Care is frequently rushed and overly dependent on patient-initiated follow-up. Providers typically devote little time to assessing function, providing instruction in behavior change or self care, or addressing emotional or social distress. Care is fragmented, with little communication across settings and providers.⁴

The question we pose in this paper is “what does good care look like?” The question is vague because its answer depends upon the level and place of care, as well as perspective. For example, good self-care will be different from good care performed by family at home, which will be different from care in an institutional setting. With this in mind, our goal is to distill certain traits that should appear in long-term care and that promote better outcomes.

We conducted a survey, trying to get various points of view concerning what good care looks like. Incorporated into this paper are various responses to an online survey we conducted. The survey was sent to over 2,000 email addresses. We had 127 responses. Of those, 53.2% indicated they work in the health care field or are a health care professional. Among the respondents were 12 nurses, 32 social workers, 23 attorneys, 4 health care administrators, and 6 financial planners. The first response we share concerns perceptions about the need for long-term care.

4) Based on your experience, what percentage of the elderly will need some form of long term care beyond rehabilitative therapy?

less than 1%	0.0	0
between 1% and 5%	0.8	1
between 6% and 10%	2.4	3
between 10% and 15%	4.7	6
between 16% and 25%	15.0	19
more than 25%	70.9	90

³ *Id.*

⁴ See Chen et al, *Best Practices in Coordinated Care*, Mathematica Policy Research, Inc. (March 2000), at <http://www.mathematica-mpr.com/publications/PDFs/bestpractices.pdf>; this report was commissioned by the Centers for Medicare and Medicaid Services, and is quoted in *Patient-Centered, Physician-Guided Care for the Chronically Ill: The American College of Physicians Prescription for Change* (American College of Physicians October 2004), at http://www.acponline.org/hpp/patcen_chronill.pdf.

Total Responses: 127

“Long-term care covers a diverse array of services provided over a sustained period of time to people of all ages with chronic conditions and functional limitations. Their needs for care range from minimal personal assistance with basic activities of everyday life to virtually total care.” Institute of Medicine, *Improving the Quality of Long-Term Care*, p.36 (National Academy Press 2001). Long-term care is typically how we help those with functional deficits cope between acute care situations (i.e. doctor visits). It is a day-in-day-out process. The doctor we interviewed described it as the journey from health to death. In this paper, we are looking for a method of evaluating long-term care to determine what good care looks like.

Consistent with the definition above, the need for long-term care arises with the onset of a functional deficit. Functional deficits are usually defined in terms of assistance needed with activities of daily living (ADLs) and instrumental activities of daily living (IADLs). In general terms, ADLs are things we do for ourselves and are highly personal. IADLs, although they may implicate privacy and would still be personal, are more closely associated with interacting with society.

What is “Good” Long-term Care

In speaking with health care providers, we received various responses to the question “What does good long-term care look like?” Perhaps the most concise came from a nursing home administrator: good care is “happy patients.” An assisted living facility administrator told us that good care is knowing someone care and is caring. Another assisted living facility administrator told us that good care feels like you’re living at home or living with family members; it includes eating well, having basic needs met, living independently as long as possible – not having anything taken away. A nursing home administrator told us that good care is qualified; that its specialists meeting the patient’s needs; it requires a knowledge base to provide care and requires knowing how to approach people – significantly, when describing care of this sort, the administrator understood the need for empathy because she placed herself in the patient’s shoes. Another nursing home administrator said good care is treating the patient like an individual.

We have several thoughts concerning what good long-term care looks like and those thoughts drive the discussion in this paper. First, care should be **planned**. Consistent with those positions adopted by the American College of Physicians, we believe each patient should have a medical home. We also believe each patient should adopt his or her own set of goals concerning quality of life and that this should be done in a context separate from the treating health care provider to eliminate any appearance of conflict. Second, long-term care should be **accessible**. If a patient cannot access care, then needs remain unmet. Third, long-term care should be **proactive**. We should not wait until an injury occurs to develop a plan for providing care. Whether a particular plan is put into effect may be a function of patient choice, but care should be forward-looking and designed to minimize the likelihood that someone who is aging in place declines unnecessarily. Fourth, long-term care should be **systematic**. This is not to say

that individuality is ignored; it simply recognizes that many tasks associated with long-term care are routine and a system should be in place to ensure that care is provided as needed. Fifth, care should be **individualized**. While the medical literature indicates that as we get older, we become more different, we remain a society of “doer’s” rather than “listeners.” We focus on task efficiency, forgetting that we are dealing with people. Good care is not simply the absence of bad outcomes; it is the enhancement of quality of life. Sixth and closely related to the fifth, care should **involve the patient** and should answer questions. Good care is interactive, invoking the informed consent process. Good communication and comprehensibility are essential to the process of involving the patient. Seventh, care should be **comprehensive**, at least in the sense that it is holistic and meets the patient’s needs and desires. It should account for a person’s physical, mental and psycho-social well-being. Eighth, good care should be **measurable**. There should be standards for determining whether care is meeting the needs of the individual and appropriate care should be provided at each instance when it is needed. Ninth, long-term care should be **consistent**. Although consistency is related to measurability and systematic delivery, we believe this concept differs enough for separate discussion. Finally, providers must be **accountable** to their patients. Accountability comes in many forms such as market choice – if a provider is non-responsive then the patient simply goes elsewhere. Accountability may, however, take other forms such as through litigation. Other important principles that are not considered in this paper include: health care should be affordable, cost efficient, and should seek to meet the needs of underserved populations.

Good care invokes not just consideration of what is done, but how, where and for how long it is done. These considerations take into account patient preferences as well as the preferences and abilities of caregivers. These considerations necessarily require exploration of what older people want from long-term care. We believe most elders want to remain home. Elders want to maintain independence for as long as possible, although the meaning of independence will vary from person to person. We also believe that most elders want to manage change.

Before examining the care concepts described above, we first explore many of the stops along the continuum of care. An individual’s journey along the continuum of care begins when his or her functional independence declines. Here is a closer look at some of the options available to people needing assistance.

Continuum of Care

Long-term care is provided over time as individuals with chronic illnesses decline in health.⁵ Most long-term care is provided at home by family members. When informal care is no longer possible, Elders enter the formal long-term care system. Individuals receiving long-term care tend to move from left to right on what we call the Elder Care Continuum. On the left side of the continuum is home, and those with no functional deficits or few care needs tend to be there. On the right side are those with total care

⁵ 107 of 124 survey respondents agreed that long-term care is a continuum. 11 indicated that it is not and 6 did not know.

needs. This tends to be nursing home care. Between these extremes, a panoply of options exists, some of which are described below.

Home

Elders want to stay home. Home can mean anything, but generally speaking, it is where an individual chooses to live. Prior to functional loss, individuals tend to adapt to their environment. After onset of functional loss, the environment often times must adapt to their needs. When the physical environment can no longer be adjusted to meet the needs of the elder, then additional caregiver resources are required, or a change in environment may be necessary.

Most long-term care is provided at home by family and friends. Isolation, because the Elder is single or after loss of a spouse, often results in a move to a more formal setting. Other conditions leading to a change in housing situation include loss of the caregiver support system, need for assistance with medication management, fear of falling, falls resulting in injury, acute episodes coupled with fear of recurrence or with a decline in condition, wandering, and incontinence. The need for rehabilitation can result in a short-term stay away from home, with the average rehabilitation time being 30 to 40 days.

Home with Family Assistance

Most caregiving is done at home by family members. Most often it is unpaid. It can range from giving “mom” a ride to the doctor’s office to providing total care. Unless an elder is being abused, there are no laws requiring admission to a formal long-term care institution. However, statistics tell us that because caregiving is hard work, over time caregivers need assistance. Caregiver burnout is not uncommon. Caregivers tend to suffer deleterious mental health effects and from physical problems including increased blood pressure and insulin levels, impaired immune systems and an increase in cardiovascular disease.⁶ When the family network breaks down or, preferably *before it breaks down*, outside assistance should be summoned.

5) Most long-term care is provided:

	Percentage	Responses
at a hospital	0.8	1
at a rehabilitation center	0.8	1
at home by family	60.6	77
at home by home health care	4.7	6
at an assisted living facility	3.9	5
at a nursing home	24.4	31
Other	4.7	6

Total Responses: 127

⁶ http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=439.

Personal Care Services

Many providers offer home-maker assistance and assistance with non-skilled needs. Services may include self-care assistance such as help with bathing, eating, dressing and toileting or household assistance which includes housekeeping, laundry, meal preparation, shopping and bill paying. Other services such as transportation, sitter/companion and medication monitoring are available. Services are generally available 24 hours a day seven days a week, although round-the-clock care would likely exceed the cost of nursing home care.

Home Health Care

Home health agencies provide skilled nursing and rehabilitative care such as physical, occupational and speech therapy. Often, agencies providing these services will provide ancillary personal services as well. These services are particularly important when the Elder requires regular medical care that is beyond the knowledge and experience of family caregivers.

Adult Day Care

These programs provide social activities, meals, assistance with personal needs, health education and supervision in a safe environment on a temporary basis. Most centers are open Monday through Friday during normal business hours and allow full-time caregivers an opportunity to continue their daily work routine while providing supervision and care for the elderly person.

Respite Care

Respite care offers relief for home caregivers by allowing overnight accommodations as well as medical and social supervision in a nursing home or an assisted living facility.

Homes for the Aged

These facilities are designed to provide a place where people who are able to care for themselves with little or no help, may receive room, board and limited personal services. Someone who lives in the home must be physically and mentally capable of finding his or her way out of the building in case of an emergency without the assistance of another person. They are neither staffed nor licensed to provide medical care. Depending on amenities, they may range from apartment style living to something that looks more like a country club.

Continuing Care Retirement Communities (CCRCs)

Continuing care retirement communities (CCRCs) offer seniors long-term contracts that guarantee lifelong shelter and access to specified health care services. In return, residents usually pay a lump-sum entrance fee and regular monthly payments. Depending on the contract, the entrance fee may be nonrefundable, refundable on a declining basis over time, partially refundable, or fully refundable. CCRC residents enjoy an independent lifestyle with the knowledge that if they become sick or frail, their needs

will continue to be met. These communities provide a continuum of care from independent housing through skilled nursing care.

Assisted Living Residences

Assisted living is a long-term care option for Elders that is frequently built on a social, rather than medical, model. ALFs are for individuals who need some assistance, but do not require the nursing care provided in a nursing home. These facilities are regulated. Although regulations will differ from State to State, in many areas, they are allowed to help administer medications to the resident. Typically, there are no bed-bound residents.

Among those services provided at assisted living facilities are meal preparation, assistance with medication management, housekeeping, and standby assistance with bathing, dressing, and grooming. The routine provided in this setting will frequently contribute to improvement or stabilization of the resident's condition. Frequently, home health care can provide therapy or other services in the assisted living home to extend a resident's ability to stay. Residents who live in assisted living are usually required to transfer independently and must be able to exit the building independently during emergencies. Many assisted living facilities today operate under a hospitality model, leading one person we interviewed to liken them to a docked cruise ship. Residents who enter this level of care typically remain there for two to five years.

Typically, resident danger is associated with an improper admission or an untimely discharge. Proper care at this level will include a comprehensive assessment to determine whether an admission is appropriate (e.g., will the resident be safe) and will also establish a baseline. The facility should monitor the resident's condition on a regular basis and if a decline in condition would put the resident in danger, then the resident should be discharged to a higher level of care. Conditions that typically result in the need for a higher level of care are the progression of dementia, or the need for skilled therapy. Counseling is frequently necessary when a resident must be discharged because either the resident or the resident's family is in denial.

Memory Care Units

More and more assisted living facilities are establishing memory care units. These units operate on the same social model as other ALFs, but have locked units to prevent wandering.

Nursing Homes

The job of a nursing home is to provide 24-hour nursing care to those who are chronically ill or injured, have health care needs as well as personal needs and are unable to function independently. The team of caregivers in a nursing home includes the administrator, a physician who serves as the facility's medical director, registered nurses, licensed practical nurses, certified nursing assistants, a dietitian, activity coordinator, social worker and housekeeping staff. Nursing homes may provide two levels of care: intermediate care and skilled care. Intermediate care is typically custodial, although it functions at a higher level than any other care setting. Skilled care provides the residents with more extensive services such as physical, occupational, speech or

respiratory therapy. Many nursing homes have an Alzheimer's unit which is typically secured.

One of the primary problems with nursing home care is the stigma attached to them. Many elders still envision them as the county "old folks home" or the "poor house." Many people have an expectation that those admitted to a nursing home will get worse, or that a nursing home is a place to die. Sometimes these stigmas lead to depression, which in turn impacts recovery.⁷ One nursing home administrator indicated that the best way to confront these out-dated notions is by having people visit the nursing home. Many nursing homes have moved toward hotel style amenities and one administrator indicated that within ten years, consumers will expect nursing homes to deliver medical care "hotel-style."

One nursing home administrator indicated that learning the resident's story can contribute to better care. It personalizes the resident. For those who come into the nursing home cognitively intact, the staff can talk to the resident. For residents with dementia or other conditions that prevent dialog, it is important for family members to let the staff know who Mom or Dad were before their condition declined. "Local" nursing homes sometimes have an immediate bond with residents because staff members knew the resident prior to admission

More data exists concerning the quality of nursing home care than any other level of care. This is because most nursing homes accept Medicare and Medicaid funds and, therefore, are subject to inspection and reporting requirements. According to the IOM Report "[e]vidence indicates that the quality of nursing home care in general has improved over the past decade, even though nursing homes are serving a more seriously ill population." This appears to be consistent with other data, such as a GAO report from July 2003 titled *Nursing Home Quality: Prevalence of Serious Problems, While Declining, Reinforces Importance of Enhanced Oversight*.⁸ There, the GAO reported that the magnitude of problems uncovered during standard nursing home surveys remains a cause for concern even though OSCAR⁹ deficiency data indicates that state surveyors are finding fewer serious quality problems. Most of the serious survey deficiencies seem to be coming from the same underperforming nursing homes.

Hospice Care

Traditionally hospice care is provided at home. It is palliative care, not curative care, for the terminally ill. It addresses not only physical needs and pain management but also psychological, spiritual and emotional needs for residents, family members and friends. Hospice care is provided through an interdisciplinary, medically directed team.

⁷ One administrator we interviewed indicated that the loss of personal control associated with the conditions leading to a nursing home admission can lead to depression.

⁸ <http://www.gao.gov/new.items/d03561.pdf>.

⁹ OSCAR is the Online Survey, Certification and Reporting system maintained by CMS. It is described at http://www.ahca.org/research/oscar/OSCAR_readme.pdf.

This team approach to care for dying persons typically includes a physician, a nurse, a home health aide, a social worker, a chaplain and a volunteer. Hospice requires a doctor's order with a prognosis of 6 months. For those who qualify, hospice services are paid for by Medicare and the room and board at the nursing home is paid for privately or by Medicaid. The resident liability which is paid monthly to the nursing home is discontinued. Many times the family benefits more from the services than the resident.

The Chronic Care Model

The Chronic Care Model for the delivery of health care 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.”¹⁰ 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 information systems.¹¹ 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.”¹² 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.¹³ 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.¹⁴

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 current model assumes a face-to-face contact between

¹⁰ <http://www.improvingchroniccare.org/change/model/components.html>.

¹¹ *Id.*

¹² RAM Leadership Group, *Resources: Leadership Guide, Section 16.1 – Chronic Care*, http://www.ramcampaign.org/pages/RAMLeadershipGuide-Campaign_Issues_Chronic-Care.htm.

¹³ The entire series is available at <http://www.researchchannel.org/prog/displayseries.aspx?fID=804>.

¹⁴ “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.

the patient and the doctor, hospital or other institutional provider.¹⁵ Good chronic care management, on the other hand, typically takes place between face-to-face contacts.

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.”¹⁶ In this climate, one rightly asks “Who stands with the patient?” Who will press for all of the options available, and not just for 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 they infuse their own views into the care plan.¹⁷

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.¹⁸ Holding others accountable, though, is what lawyers do for their clients.

Physiological Changes Associated with Aging

Aging has been defined as the collection of changes that render human beings progressively more likely to die (Medawar, 1952). Individuals age at different rates due to lifestyle choices, environmental factors and genotypes. Various changes in condition are beyond the scope of this paper, but they are discussed at the following websites:
<http://www.merck.com/mrkshared/mmg/sec1/ch1/ch1a.jsp>
<http://www.senescence.info/definitions.html>
<http://www.geriatricsyllabus.com/syllabus/main.jsp?cid=AGE-AGE-1>

Some persistent problems in long-term care settings that practitioners should be aware of are pain, pressure sores, malnutrition, dehydration, and urinary incontinence.

¹⁵ 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.

¹⁶ D. Stone, *Shopping for Long-Term Care*, 23 *Health Affairs* 191, 196 (2004).

¹⁷ 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 course of treatment. M. Mahar, *Money-Driven Medicine: The Real Reason Health Care Costs So Much* (Collins 2006).

¹⁸ Medicare ‘Pay for Performance’ Initiatives, <http://www.cms.hhs.gov/apps/media/press/release.asp?Counter=1343>.

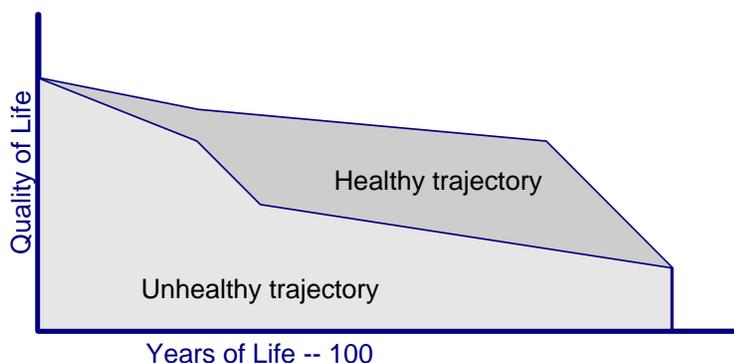
Most of these conditions can be identified by evaluating the patient or by reviewing lab results.

Good care is planned

At present, the health care system is fragmented and patients become lost in the system. Patients are passed from physician to physician, from institution to institution with little coordination. Family doctors find it difficult, if not impossible to track where their patient is, let alone keep up with their condition. Compounding matters, the financing system works against physicians who attempt to spend time counseling patients. The current financing system rewards physicians on a task basis, paying per visit or per condition, rather than compensating them based on performance. Physicians who attempt to spend additional time with patients go unpaid. The current climate caused the physician we interviewed to declare that the doctor-patient relationship is dead. Physicians and other health care providers have an economic incentive to get patients in, treat the condition complained of and get to the next patient as efficiently as possible.¹⁹

The combined effect of fragmentation and loss of the traditional health care “quarter-back” means that many patients wander through the system without coordinated care. The burden is on the patient to track medical records, keeping lists of problems, medications and copies of important records.²⁰ Patients and their advocates must undertake this task to keep information accessible when it is needed. During our physician interview, it was suggested that a brief, concise narrative should be maintained by the family.

Another reason for planning is to improve outcomes. The chart to the left illustrates a conversation we had with a physician. He indicated that a patient with a healthy trajectory maintains a high quality of life until shortly before death, with



¹⁹ “High quality care is unlikely to flourish in an environment that leaves physicians demoralized and leads many to believe that the standards of care have been compromised. Our results suggest that the goal of providing high quality care may be better approached by the use of limited financial incentives based on the quality of care and patient’s satisfaction than incentives that reward physicians for restricting access to specialty care or for squeezing in a greater number of visits per day.” *Patient-Centered, Physician-Guided Care*, *supra*, p. 10, quoting an unidentified article in the New England Journal of Medicine.

²⁰ “Physicians are frequently left to prescribe treatments based on incomplete and/or inaccurate patient information, often relying on patient memory alone.” *Patient-Centered, Physician-Guided Care*, *supra*, p. 5. Although the preferred system fix is more coordination, keeping a personal record may be the best second-choice.

death resulting from a sudden event such as a heart attack. An unhealthy trajectory includes a diminished quality of life occurring earlier and continuing over an extended period of time. Although unhealthy behavior will take its toll, patients who are counseled to discontinue unhealthy behaviors, and who follow that advice, can move the trajectory upward, improving quality of life during their remaining years.

Planning includes care management. “[T]here is slowly accruing, though not universally embraced, evidence that case management of the chronically ill can have a significant positive impact on the quality of patient care and reduce costs, when compared to receiving care in a fragmented, hit-or-miss fashion.”²¹ At present, however, the health care system as a whole fails to provide this type of coordination. Thus, those Elder Care Coordinators willing to step into the patient’s life and help quarterback care are providing a valuable service. In most instances, non-physician care management will be more limited but it can still serve the function of coordinating communication both by encouraging the communication of patient data to providers and by coordinating interactions among health care team members.

Finally, planning allows patients to consider and develop a personal long term care plan. Patients should ask questions such as “where do I want to die” and “how do I want to die.” A detailed plan for care relieves caregivers from the burdens associated with health care decisions by, for example, letting them forego unwanted therapies in favor of hospice. At present the long-term care system focuses on quantity of life more than quality of life. Physicians and health care providers are reluctant to suggest hospice because it is viewed as “giving up.” According to the doctor we interviewed, they look to third-parties, such as Elder Law Attorneys, to provide this advice since attorneys have no stake in the treatment plan and are better positioned to counsel patients concerning preferences and rights, and -- to *defend* the patient choices.

Good care is accessible

Accessibility incorporates several concepts. At its most basic level, it is a right of access or approach, but it also incorporates the element of timeliness. Access to care that comes too late is like closing the gate after the cows are gone. Its value is limited at best.

Access also incorporates the concept of appropriate care. Access to an eye doctor does nothing to resolve a dental problem. In the long-term care setting, access to nursing home care is not necessarily the most appropriate care when social support (e.g., care in assisted living) is what the elder needs. Access should be measured against the patient’s needs.

In the United States, health care is a commodity, not a right. Access is purchased, not simply provided based on need.²² Although we know individuals who “spend down”

²¹ *Patient-Centered, Physician-Guided Care*, p. 13.

²² Of those surveyed, One Hundred Twenty Five people responded to our question “Are financial considerations important in determining what care will be provided.” One Hundred Eleven people said “yes,” while Fourteen said “no.” More problematic is the problem of foregone treatment. “People with chronic conditions whose families have medical bill problems are four to five times as likely to forgo or delay care because of cost concerns as those whose families reported no medical bill problems.” H. Tu,

generally have access to long-term care financing through Medicaid, there is no guarantee that appropriate services will be available. Providers may refuse to accept Medicaid,²³ or services may not be offered with the geographic area where the patient lives. Choices may be limited based on what Medicaid is willing to fund (e.g., there is an institutional bias within the Medicaid program toward nursing home care). Further, national attention seems to be focused on access to acute care for the more than 45 million uninsured.²⁴ For this reason, it is imperative that practitioners assist elders in planning to pay for care.

If America continues to use a market model as expected, then available services will be a function of supply and demand. Twisting a phrase from *Field of Dreams*, if patients/consumers come, then providers will build it. It is reasonable to assume that demand for long-term care services will increase as the Baby Boomers age;²⁵ in fact, demand could outpace supply, absorbing whatever supply is provided, making the market supply driven. Still, we know that the market does respond to demand. This is evident as the number of nursing home alternatives has proliferated over the past ten years. The Lewin Group reported, in *Nursing Home Use by 'Oldest Old Sharply Declines* (Lewin Group November 2006), that the number of assisted living beds in the U.S. has doubled over the last ten years, largely in response to market demand. Because older Americans are healthier and wealthier, we can expect additional long-term options to evolve for those who can afford them.

Cost will remain a factor limiting access. Complicating this problem, most people don't know how long-term care is funded and, because they don't understand the system, they don't plan to meet their needs. When we asked our survey group how long-term care is funded, we had only one correct answer -- despite the fact that many of the respondents are members of the Life Care Planning Law Firms Association. The correct answer was "non-monetary assistance by family and friends." After that, 56 people responded saying "Medicaid" is how people pay for long-term care and 37 people indicated that people finance long-term care with their own money. Thirteen people indicated that most people pay for long-term care with Medicare. The point here is not the specific financing mechanism used, but that professionals remain confused concerning how people pay for care. This confusion is an impediment to planning

Rising Health Costs, Medical Debt and Chronic Conditions, Issue Brief No. 88 (Center for Studing Health System Change 2004), at <http://www.hschange.com/CONTENT/706/>.

²³ On July 19, 2007, the Kaiser Family Foundation reported, picking up a story from the Wall Street Journal, that a growing number of physicians will not accept new Medicaid beneficiaries as patients. A 2006 report cited in the Kaiser article indicates that almost half of all physicians polled said they had stopped accepting or were limiting the number of new Medicaid beneficiaries they will see. See http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=46343.

²⁴ AMA, Health Care Access: The Issue, at <http://www.ama-assn.org/ama/pub/category/16133.html>.

²⁵ One writer says the demand will "expand massively" over the next 50 years. See *How Will Boomers Pay for Long-Term Care* (Forbes July 20, 2007), at http://www.forbes.com/business/2007/07/19/longterm-health-care-biz-cx_0720oxford.html.

because people who incorrectly believe a third party payor exists will not plan to meet their own needs. Planning is needed to preserve assets and, by preserving assets, ensuring access to the system.

Health literacy is also a barrier to access. 106 survey respondents (86.9%) indicated they believe health illiteracy is a barrier. At present, due to system fragmentation, the burden of finding and getting to needed care is on the patient.²⁶ Most respondents indicated more education is needed, although there were diverse answers concerning how education should be provided. Many responded by placing responsibility for and burden of education elsewhere. In our view, health care education is everyone's concern. Some respondents indicated that a major hurdle is overcoming misinformation in the community. For example, people fail to purchase long-term care insurance because they believe, incorrectly, that Medicare will pay for long-term care.

Another constraint limiting future access is the labor market. Nurses are in short supply and few physicians specialize in geriatric care. Some argue that this is a function of payment level,²⁷ but the real issue for the future is that ratio of workers per retiree is declining. Although we are reluctant to cite any politician's statistics, President Bush correctly said that in 1950, there were 16 workers per retiree. In 2005, there were 3.3 workers per retiree. When the youth of today retire, there will be 2.1 workers per retiree.²⁸ Further complicating this is the realization that the long-term care industry consumes national resources; it rarely adds to them. Thus, one could not reasonably expect wages to be competitive, particularly for skilled employees. The long-term care industry is already competing with manufacturing and other service industries for its share of the 3.3 workers per retiree and the competition will stiffen as the ratio declines. In the future, planning that preserves the viability of family caregiving will be even more critical than it is today because the labor market may put institutional staffing levels be at-risk.

A related accessibility concept is the level of access an elder has to health care providers after they enter the long-term care system. A physician who cannot be reached by telephone and who does not visit a facility is accessible in name only. Likewise, when requests for care or services go unanswered, one can legitimately question whether care is accessible. We have previously mentioned that the current financing mechanism discourages access by failing to compensate physicians and health care providers who make themselves available. It will become more important for patients and their

²⁶ *Patient-Centered, Physician-Guided Care, supra*, p. 5.

²⁷ "Nursing homes, in which Medicaid funds care for 66% of the patients, lose an average of \$13 per Medicaid patient per day, according to a Lewin Group analysis." *How Will Boomers Pay for Long-Term Care, supra*. Of course, if this is true, one could reasonably ask why the Carlyle Group recently agreed to pay \$6.3 Billion for Manor Care. *See Manor Care to go private in \$6.3 billion deal* (MarketWatch July 2, 2007). We will not resolve this debate here. The debate concerning whether nursing homes lose money, or whether they simply hide their profit through the use of inflated rental payments and consulting fees to related entities has raged since the rise of the nursing home chain.

²⁸ President Discusses Strengthening Social Security in North Carolina (White House February 10, 2005), at <http://www.whitehouse.gov/news/releases/2005/02/20050210-8.html>.

advocates to educate themselves on health care issues, to seek counsel elsewhere, to enlist their own care coordinators, and to learn their health care rights.

Each of these issues presents an opportunity for the elder advocate. Education should lead to planning, which should make elders more prepared to choose the right care and have available financing. Once care is sought, education should empower patients to be more proactive in their care plans, enabling them to insist upon access when it is not provided.

Good care is proactive

The American College of Physicians study on chronically ill patients reports that many unplanned hospitalizations appear preventable. Good care should move proactively to prevent unnecessary complications. Interventions, including counseling, not only save dollars, but preserve quality of life.

Preventative care is defined as comprehensive care emphasizing priorities for the prevention, early detection and early treatment of conditions. There are many preventative care programs, services and schemes that are of benefit in maintaining a high level of health and well being. These include cancer screenings, government healthcare initiatives, vaccinations, and a large range of complimentary therapies. The medical literature makes it clear that early intervention reduces or controls the impact of health care problems. A recent news article claimed that if chronic care patients “were treated in a more proactive fashion, ... the country could save from \$100 billion to \$125 billion a year in health care spending.”²⁹ Substantive information concerning preventative care is available online,³⁰ as are preventative care flow sheets, including flow sheets for males and females over the age of 65.³¹

Prevention is linked to the nursing process. The elements of that process are: assessment, care planning, implementation and re-assessment. The first element provides a base-line for care. Those actions necessary to maintain current health become part of the care plan and implementing those plans tends to prevent negative outcomes. Continuous re-assessment monitors any departure from the patient’s base-line, allowing the provider to work proactively in modifying the care plan to improve the patient’s condition or to prevent other negative outcomes.

Long-term care providers should proactively analyze systems and care to eliminate hazards or failures in the care process. The principal steps in this analysis: identify potential failures in processes; identify the possible effects of failure; identify the criticality of each failure; prioritize the failure based on their criticality; identify possible causes of the priority failure; redesign the process to prevent the failure and/or

²⁹ T. Pugh, *Curbing chronic diseases new issue in health-care politics* (Kansas City Star July 26, 2007), at <http://www.kansascity.com/news/nation/story/206855.html>.

³⁰ <http://www.ahrq.gov/clinic/ppipix.htm>.

³¹ <http://www.aafp.org/fpm/20010200/preventivecareflowsheets.doc>

put in place process controls to detect the failure before the effect occurs; implement and test the new design or control process.³²

Good care is systematic

Systematic care assists caregivers in maintaining continuity of care, eliminating disparities in care, and in error prevention. Systems are a necessary aid for preventing errors and oversight when tasks become complex or routine. Systems may be as simple as a checklist or as complex as an organization structure that facilitates multidisciplinary care.

Educational and training systems are also needed and many have been developed by third parties. For example, the Joint Commission International Center for Patient Safety recently published a new website³³ designed to promote patient safety. It is an attempt to categorize information relating to patient safety, safety goals, patient safety practices, sentinel events, and related public policy.

Health care systems are also critical because most long-term care tasks are performed by non-skilled aides. Systems assist non-skilled aides in providing the right care at the right time.

Good care is individualized

Notions of privacy, dignity, choice, and self-determination imply a cooperative relationship consistent with the informed consent process. “To” is a poor preposition when modifying a health care provider’s involvement with a patient. We don’t like it when people do things “to” us. Thus, from the outset, care should be individualized to meet each person’s psychosocial needs.

Care should also be customized to meet the individual’s “needs” and preferences. Care should not be provided in a manner reminiscent of the old saying “when mom is cold, everyone wears a sweater.” Similarly, necessary care should never be withheld.

Cookie-cutter care ignores the unique needs of each patient, is blind to circumstances and may waste resources. As each patient’s condition is assessed, the care necessary to help that patient attain or maintain their highest potential should be available and offered. If accepted, it should be provided. We do not say it should be provided in every case because implicit in the concept of informed consent is the right to refuse care.

Individualized care takes into account psychosocial preferences that impact care. For example, each patient will have food preferences. Satisfying those preferences may encourage better nutritional health.

³² J.E. McDonough, *Proactive Hazard Analysis and Health Care Policy* (September 2002), at <http://www.milbank.org/reports/Proactive/020925Proactive.html#executive>.

³³ <http://www.jcipatientsafety.org/>.

Good care involves the patient

Care that involves the patient should be explained before it is provided. This is generally done by inviting the patient into the long-term care plan meeting. Conversations describing care should be in plain English or, if the patient does not speak English, in the patient's native language. Where the goal is to guard an elder's long-term care plan, or where there is a potential for family disputes, the care plan meeting should be witnessed by core family members.

Patients or their advocates should be encouraged to ask questions. In many cases, patients may not know what to ask, so when possible, good care is explained in a way that encourages dialog. Time should be provided for this process to work.

Good care also requires communication from the patient.³⁴ Patients should tell health care providers about their health history, including significant illnesses, operations, and family history. Patients should describe recent events, including information about recent changes in condition. Personal information that may bear on the care provided should be volunteered. Patient involvement enhances the success of a team approach to long-term care.³⁵

Good care should provide choices where possible. It should explain the consequences of refusing care, but should respect the patient's right to accept or decline care. Patient choices should be documented.

Good care is comprehensive

Comprehensive care begins with an assessment and is holistic, considering physical, mental and psycho-social needs.³⁶ As expressed previously, an assessment of some type should be made at each level of care. After the assessment is completed, patient choice may determine the nature of subsequent care, but a comprehensive range of options should be provided to the patient.

Comprehensive care should also be goal oriented. As mentioned above, the elder's goals for care and regarding end-of-life decisions should be considered and

³⁴ "For treatment to be successful, patients must be well informed about their disease, know where they can access treatment, and must have greater control over their treatment." *Advances in Managing Chronic Disease: Research, performance measurement and quality improvement are key*, BMJ 2000; 32; 525-526 (26 February), at <http://www.bmj.com/cgi/content/full/320/7234/525>.

³⁵ Good teams incorporate the 12 C's of teamwork: (1) Communication (this is the sine qua non of teamwork); (2) Cooperation (empowerment of team members); (3) Cohesiveness (team sticks together); (4) Commitment (investing in team process); (5) Collaboration (equality in the team); (6) Confronts problems directly; (7) Coordination of efforts (insuring actions support a common plan); (8) Conflict management; (9) Consensus decision making; (10) Caring(patient centered outcomes); (11) Consistency (with one another and the environment); and (12) Contribution (feeling this is being made). J. Wiecha, *The Interdisciplinary eHealth Team: Chronic Care for the Future* (2004), abstract available at <http://www.jmir.org/2004/3/e22/>.

³⁶ One administrator we interviewed spoke of the five domains: spiritual, physical, social, emotional and mental, saying each must be addressed in the caregiving process. For example, under the heading of "social," she indicated it was important to give Elders in an assisted living facility the ability to be part of and to give back to the community.

documented. The comprehensive care plan should take these goals into account and should be structured to maintain quality of life.

One barrier to comprehensive care is system fragmentation. The concept of a medical home, discussed above, tends to resolve this issue by bringing all of the Elder's treatment information to one physician (or other qualified provider) for review. The American College of Physicians study advocates resolving the fragmentation issue by implementing a patient-centered, physician-guided³⁷ model that includes a case management fee.

Good care is measurable

Suggesting that good care is measurable implies a certain level of quality. The Institute of Medicine, in its 2000 report, said: "Defining or evaluating quality of long-term care is fraught with problems, made more difficult by the unevenness of the available empirical evidence. Information to evaluate quality of care in nursing homes is extensive and systematic, but for most other settings it is nonexistent or very limited and lacking in uniformity."

Care designed to meet patient goals should be evidence-based. It should put patient needs first, should optimize quality of care, and should squeeze out waste. One policy goal is to control costs by eliminating needless procedures, sometimes called futile care. However, without measurable standards and an understanding of expected outcomes under particularized circumstances, it is impossible to know which care is futile and which care might improve the patient's condition. Certainly, without measurable standards, any decision to discontinue a treatment option is subject to being second-guessed.

Good care is consistent

Consistency is particularly important in long-term care because it takes place over an extended period of time. By definition, a patient's needs are being addressed. If there is a lapse in consistency, then needs go unmet.

Good care is accountable

Accountability is an enforcement mechanism that takes many forms, ensuring adjustments when good care is lacking, or when care is poor. In a market model, accountability may mean that consumers with the ability to choose take their business elsewhere. Accountability concepts become more troublesome when consumers lack choice. In those situations, third-party enforcement of quality standards is appropriate. Accountability may take place through credentialing process, through licensing, regulatory enforcement and through litigation.

³⁷ "Physician-guided means having all of a patient's health care needs supervised, monitored and overseen by a physician care team leader/coordinator, presumably the patient's primary care physician, a role doctors of internal medicine are best qualified to fill." *Patient-Centered, Physician-Guided Care*, *supra*, p. 4.

Even so, other more pragmatic and immediate forms of accountability should not be overlooked.

Conclusion

Good long-term care does not simply occur; it is a day-in-day-out process. It requires committed individuals who care about the people they serve. Care management can contribute to good care by improving communication and coordination of care.