

# Protecting Seniors' Autonomy

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NAELA Advanced Practitioners Invitational Program

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## I. Autonomy

A. An individual's right to live life consistent with his or her personal values is one of the fundamental principles of a free society. For the better part of a millennium, anglo-american jurisprudence and public opinion have developed around the concept that every person is in control of his or her own destiny. In this view, the role of society (and its representative, government) is limited to the least restriction on personal liberty consistent with the public good.<sup>1</sup>

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<sup>1</sup>In 1690 John Locke wrote, in his *Second Treatise of Government*, that the power of a legislature "is *limited to the publick* good of the Society. It is a Power, that hath no other end but preservation, and therefore can never have a right to destroy, enslave, or designedly to impoverish the Subjects." Nearly a century later, in 1762, Jean-Jacques Rousseau's *The Social Contract* posited that the only control the sovereign has over his subjects is the control ceded by the individuals to government for the general good. Consequently, the sovereign power "does not, and cannot, pass the limits of general conventions; so that the sovereign never has a right to burden one subject more than another..."

While John Stuart Mill rejected Rousseau's invention of a social contract to explain the relationships among individuals and their government, he agreed with the result of Rousseau's logic. In *On Liberty* (1859), Mill wrote that "everyone who received the protection of society owes a return for the benefit

B. Seniors' wishes. Autonomy takes on added significance to seniors, many of whom fear the loss of their independence and their ability to control their own lives. It is of paramount importance that seniors have under their control the prerogative to decide how to live out the rest of their days and how and in what manner they will control their own property. Their ability to exercise this control and maintain their individual dignity often forms the basis for their self-esteem and their belief in their continuing viability as a person. The challenge for most professionals is to reliably determine those wishes, to sift through the influences that may have been brought to bear on the susceptible senior, and to pursue the course that the senior would request if fully competent and articulate.

## **II. The Legal System Can Act to Preserve Autonomy**

A. Health Care Decisions and Patient Self-Determination. One of the more important elements of autonomy for seniors is control over the course of their medical treatment. Most seniors worry about their personal dignity in medical settings, and they are concerned that catastrophic medical care costs could bankrupt them, cause them to lose their homes and savings, and leave nothing for their children.

1. Informed consent doctrine and assault/battery. Most of the early cases dealing with medical self-determination spoke in terms of informed consent, assault and battery or, more rarely, medical malpractice. Perhaps the most quoted language is Justice Cardozo's:

Every human being of adult years and sound mind has a right to determine what shall be done with his own body;

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and the fact of living in society renders it indispensable that each should be bound to observe a certain line of conduct towards the rest. This conduct consists, first, in not injuring the interests of one another; or rather certain interests, which, either by express legal provision or by tacit understanding ought to be considered as rights...As soon as any part of a person's conduct affects prejudicially the interests of others, society has jurisdiction over it, and the question whether the general welfare will or will not be promoted by interfering with it, becomes open to discussion." Although Mill specifically understood that the rules were different for those not possessing "the ordinary amount of understanding," the argument for limited state control over others was by then well developed.

and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages.<sup>2</sup>

2. Right to refuse treatment. With the notable exception of the Missouri Supreme Court, virtually every federal or state court confronted with the question has found that the right to privacy implied in the U.S. Constitution encompassed the right to refuse unwanted medical treatment.<sup>3</sup>

3. Federal Patient Self-Determination Act. The first attempt at federal legislation of this issue was effective December 1, 1991. From that date, all hospitals, nursing homes, and health maintenance organizations receiving federal (Medicare and Medicaid) funds are required to notify all patients of their right to make medical treatment decisions. Each state is required to develop a form describing the applicable state law and the availability of living wills, durable powers of attorney and/or other advance directives; the information developed by the state may but need not be the basis of the information provided by the health care provider. It is important to note that the Patient Self-Determination Act does not change the existing law of any state, nor does it compel any state to develop laws or regulations. All that is required is the provision of information to patients about the present status of state laws.

4. The *Cruzan* case (*Cruzan v. Missouri Department of Health*, 110 S.Ct. 2841 (1990)). *Cruzan* actually stands for the limited legal principle that states have the Constitutional authority to decide what level of proof may be required to demonstrate an individual's wishes about life-sustaining treatment.<sup>4</sup> More importantly, however, Nancy Beth Cruzan's story

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<sup>2</sup> *Schloendorff v. Society of New York Hospital*, 211 N.Y. 125, 105 N.E. 92 (1914), at page 129.

<sup>3</sup> Cf. *Matter of Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985); *Matter of Welfare of Colyer*, 99 Wash.2d 114, 660 P.2d 738 (1983); *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977); *Bouvia v. Superior Court*, 179 Cal. App.3d 1127, 225 Cal.Rptr. 297 (1986).

<sup>4</sup> For an excellent explanation of the legal significance of the *Cruzan* case, plus a compelling description of the personal and legal trials of the

galvanized the nation and transformed the nature of the debate on individual autonomy in health care. Her gastrostomy tube was removed on December 14, 1990, and she died twelve days later.

5. Advance directives. Most states by legislation, case law or common practice recognize at least two types of advance directives: “living wills” and durable health care powers of attorney. The former may constitute a writing directing the type of treatment the signer would wish in various circumstances (which may be described specifically or generally). The latter may designate another person to make the decision and authorize treatment or withholding of treatment; a health care power of attorney may (but need not) direct the agent to act in a particular manner. Some states utilize different language (e.g.–“health care proxy” rather than power of attorney), but the purpose and value of the documents remains the same. Thoughtful use of both types of instruments in combination should increase the autonomy of seniors.

6. “Do Not Resuscitate” orders. A special kind of problem arises in the case of the anticipated death, or for patients who have particular concern about CPR or other forms of resuscitation. While patients may have a Constitutional right to refuse even CPR, medical protocols usually require intervention and laws immunize physicians and emergency medical technicians from any liability for acting in emergencies. A handful of states have enacted legislation to permit patients to refuse resuscitation in advance.<sup>5</sup>

7. Specific medical procedures. In order to maximize self-determination, as much specific detail as possible should be included in advance directives. Among the medical terms and procedures that seniors, family and workers should be familiar with and consider referring to in advance directives are:

- a. Nasogastric, gastrointestinal and intravenous food and fluids. Specificity is important to the medical community, though less so

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Cruzan family, consider “Long Goodbye: The Deaths of Nancy Cruzan,” written by William H. Colby (the attorney who took the case to the U.S. Supreme Court) and published in 2002 by Hay House, Inc.

<sup>5</sup> Cf. Montana Code Ann. §50-10-101 *et seq.*

in the developing case law. The courts have not always clearly articulated an understanding of the different forms of food and fluid administration, the medical community's opinion of the effect of withholding food and fluids, and the recent advances in medicine involving direct placement of stomach tubes.

b. Respiration. Many of the cases dealing with the right to refuse treatment, especially in the first years after Karen Ann Quinlan's case became an issue for public discussion, deal with artificial respiration. This is the area most frequently associated with "turning off the machines" in the public consciousness. Termination of artificial respiration is by now a comparatively well-settled area of the law, though the practitioner should be generally aware of the advances in medicine permitting long-term respirator use since Quinlan.

c. Antibiotics. Largely unresolved and arguably more important than food, fluid and respiration is the treatment of pneumonia (known in earlier times as "the old man's friend") and other common infections. Patients may not have considered this area of treatment, and may have mixed feelings. Any strong feelings should probably be reflected in the powers enumerated in the power of attorney, and also addressed in a personalized declaration (or living will).

d. Pain relief. A major area of concern for cancer patients and those at risk for cancer is alleviation of pain. Language permitting large doses of pain medication, even though potentially life-threatening, may significantly enhance cooperation from favorably-inclined physicians.

B. Placement. Many elderly persons report that they fear the loss of their independence more than they fear dying or even abuse.<sup>6</sup> Most seniors strongly prefer to spend the rest of their lives in the one place where they are

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<sup>6</sup>Patricia A. Parmelee, *Protective Services for the Elderly: Do We Deal Competently with Incompetence?*, 2 L. & Pol'y, 397,415 (1980); Sherry L. Willis, *Assessing Everyday Competence in the Cognitively Challenged Elderly*, in *OLDER ADULTS' DECISION-MAKING AND THE LAW* 87 (Michael Smyer et. al. eds., 1996).

comfortable, where they have fond memories, and where their families and friends can most easily find them - at home. Therefore, to the extent possible, care should be taken to allow the senior to remain home. Many seniors have a fear of going to a nursing home. There are many more placement options available today. In considering caring for a senior, the least restrictive placement option should be utilized. The challenge is weighing the level of care necessary and the senior's desire to remain independent while taking into account the ability to pay for the most favorable placement option. Less restrictive (that is, less restrictive than a nursing home) placement options include:

1. Home Care. Home care encompasses a wide variety of services and levels of care. Home care is provided by both nonprofit agencies and for-profit franchises. Some seniors can be cared for at home by one caretaker who visits a few times a week, or every day. Others may require live-in assistance, perhaps from family members (or a combination of family and paid caregivers). At the other extreme, home care can duplicate the highest level of care provided by skilled nursing facilities (or even hospital care), but usually at a tremendous cost. While home care is the stated preference of most seniors, the practical realities of providing medical care at home may make it prohibitively expensive, particularly if the resident requires round-the-clock nursing care. The cost of that level of care will probably be four or five times the cost of comparable nursing home care. The cost of occasional home visits, housework, and assistance with meal preparation (a typical combination for the largely independent senior) may be a fraction of any of the other care alternatives.

One of the major impediments to use of home care is often the concern of family members for the safety of the compromised senior. After an incident involving a stove left on until pans are burned, or strangers permitted into the home inappropriately, or any of a myriad of other dangerous behaviors, family and surrogates will often determine that it is the senior's best interest to move him or her to a more restrictive (and therefore "safer") environment. This may, however, fail to consider the effect of the move itself, the real likelihood of danger or injury in the home, the availability of less dramatic methods of reducing risk, or the wishes (long-standing and/or current) of the senior. All should be taken together in an attempt to balance the risks associated with remaining in the home against both the risks inherent in the proposed placement and

the effect of any move from the home on the already fragile state of a partially disabled senior.

2. Board and care facilities. More commonly referred to today as adult care homes, these facilities usually provide room and board for four or five to twenty or more elderly residents. While private rooms are usually available, most adult care home residents will share a room with at least one other resident. All meals and social activities are provided at the home, which frequently will be owned and run by a resident manager or an owner who lives nearby and spends most days working at the home. Most elderly residents find adult care homes to be quieter, more home-like, and more pleasant than nursing homes, although adult care homes usually are unable to deal with serious medical conditions. As a result incontinence, the need for breathing assistance or tube feedings, or any other serious medical condition will probably result in the transfer of the resident to a nursing home. The costs of adult care homes also vary widely, but may typically be between half and two-thirds of the cost of a nursing home in the same locale.

3. Congregate living. Large apartment-like complexes may house many elderly residents who have access to a common dining room and activities but also have individual apartments with kitchens (and perhaps with spare bedrooms). Although there may be nursing staff on site, the primary focus of congregate living facilities is to provide a comfortable, supportive apartment setting where residents may, but need not, participate in services. Typically, congregate living arrangements provide two meals a day (perhaps a single meal on Sunday), programs, excursions and social events. The residents may be expected to provide their own third meal. Independence is encouraged, but limited support is available when needed. Congregate living costs may vary from as little as the cost of a nice apartment complex in the area to as much as a nursing facility.

4. Assisted living facilities. A more recent development, assisted living facilities provide an apartment-like setting, accompanied by on-staff nursing assistants and oversight. Meals are usually provided in a central dining facility, and staff regularly check on residents every day. Group activities may help maintain mobility, orientation, and socialization. Costs for assisted living facilities may vary through about the same range as nursing homes, though they will generally be less expensive than

comparable nursing facilities. Much of the higher cost of some such facilities comes from additional amenities: better food, private apartments, nicer common areas, and more activities, for example.

C. Guardianship and Conservatorship. Incapacity is the legal status that occurs when a person's autonomy becomes either partially or totally impaired. When a person's autonomy becomes impaired, public policy justifies others stepping in to make choices on the person's behalf to promote the person's best interests and to protect the person from harm.<sup>7</sup> This process of "stepping in" is to appoint a guardian and conservator for the incapacitated person. A guardian is granted legal right by the court to make health care, housing, and other life decisions for a mentally incapacitated person. A conservator is granted legal right by the court to manage the assets of a person determined to be in need of protection. Guardianship (control of the person) and conservatorship (control of the finances) frequently represent the ultimate loss of personal autonomy. As a consequence, legal safeguards are of great importance, and the use of court proceedings should be viewed as a last resort, to be exercised only after the failure of all alternatives.

1. Limitations. Most states impose some limitations on the powers of a guardian or conservator, including limiting the guardian's power to involuntarily commit her ward to a mental health treatment facility. In addition, there is a growing recognition that limited guardianship (of the person) and/or conservatorship (of the estate) is generally preferable to plenary appointments, and that protective proceedings should be tailored to the actual needs of the ward while respecting personal autonomy and independence to the extent possible.<sup>8</sup>

2. Effect of guardianship and conservatorship on ward. In addition to the (often entirely theoretical) infringement on personal liberties, the social and emotional impact of a guardianship and/or conservatorship on the

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<sup>7</sup>Robert P. Roca, *Determining Decisional Capacity: A Medical Perspective*, 62 Fordham L. Rev. 1177, 1191 (1994).

<sup>8</sup>Cf. Arizona Revised Statutes §14-5303(A)(8): "If a general guardianship is requested, the petition must state that other alternatives have been explored and why a limited guardianship is not appropriate. If a limited guardianship is requested, the petition also must state what specific powers are requested."

ward must be considered. The natural human tendency of caregivers and surrogates is to eliminate all risk of danger; the result of such conservative approaches can be devastating to the subject of the proceedings.<sup>9</sup>

Of course, the problem of surrogate decision-makers attempting to eliminate (rather than merely control) risk is not unique to guardianship and conservatorship proceedings—it regularly occurs in management by agents (under general or health care powers of attorney) and family members exercising authority under state surrogacy statutes. One of the most important elements of maximizing autonomy and independence for necessarily dependent seniors, then, is to educate, support and counsel surrogates on the importance of imposing the least restrictive control mechanisms possible—even though some significant (but tolerable) level of risk remains.

### 3. Planning for Incompetence

- a. Durable powers of attorney (health and financial). The ubiquitous planning instrument of the past decade has been the durable power of attorney. A well-drafted power can dramatically reduce the likelihood that the senior will ever be embroiled in the

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<sup>9</sup>Jeffery Good & Larry King, “I Am Not A Criminal...”, St. Petersburg Times, Dec. 16, 1986, at 13-A. One elderly person for whom a guardian had been appointed observed: “I cannot tell you how much worse my mental condition is since I have been a ‘thing’ of the court’s without rights. I want to die, I pray to die. There is no happiness in my life - my life is over. I would prefer death to living as a guardianship zombie the rest of my life.” *reprinted in* Abuses in Guardianship of the Elderly and Infirm: A National Disgrace, a Briefing of the Chairman of the Subcommittee on Health and Long Term Care, Select Committee on Aging, House of Representatives, 100<sup>th</sup> Congress, 1<sup>st</sup> Sess. (Sept. 25, 1987), Comm. Pub. No. 100-641, U.S. Gov’t Printing Office, Washington, D.C. (1988).

An American Bar Association staff attorney has also observed that “[a] lot of older people are afraid they’ll be put in a nursing home, or they’re afraid that they’ll have a guardian appointed for them, and they’d rather be abused than have either of those things happen to them.” Abuse of the Elderly on the Rise, National Public Radio, Morning Edition, May 16, 1995 (quoting Lori Stiegel, ABA staff attorney).

legal morass of guardianship and conservatorship. Equally importantly, such documents maximize the probability that the wishes of the senior will be carried out, even though the decision is actually made and implemented by a surrogate.

b. Living Trusts. A thoughtfully crafted trust can also maximize the personal autonomy of the senior, while helping to limit the possibility of guardianship or conservatorship. For example, trust provisions might include an express declaration that the trust corpus be used to maintain the trustor at home without regard to the effect on ultimate beneficiaries, or that trust assets not be expended on some kinds of care (or care settings). The goal is to craft trust instruments (and powers of attorney) to express the actual wishes of the senior.

4. Driving. Seniors usually have a tremendous fear of losing the ability to drive and the freedom that driving affords. Transportation for the overwhelming majority of Americans means the personal automobile. People of all ages love the car because it allows us to operate on our own schedules. We depend on our cars for the ‘essentials’ such doctor’s appointments and grocery shopping. Our cars allow us to enrich our lives by driving to see friends, go to the movies, visit state parks, and worship.

a. Older drivers are different. Statistics show that the highest risk of crash per mile driven is in the group of drivers 65 and over. The accidents they tend to be involved in frequently involve other cars.

b. Maintaining independence in driving and driving decisions. It is important to allow a senior to drive for as long as it is safe for him or her to do so. Planning ahead for the time when that is no longer possible is a good way to recognize the importance of driving and the needs that will arise if he or she is unable to do so. There are several methods in which one can plan for the time when driving may no longer be an option.

i. Talk with family members and/or friends and research with their assistance what public and private transportation alternatives exist in your area.

ii. Draft an “Agreement With My Family about Driving,”

perhaps along these lines:

I have discussed with my family my desire to drive as long as it is safe for me to do so. When it is not reasonable for me to drive, I would like \_\_\_\_\_ or \_\_\_\_\_ to tell me that I should no longer drive. I wish for \_\_\_\_\_ to assist by consulting with my physician or a driving rehabilitation specialist about my ability to drive safely. If I am unwilling or unable to surrender my driver's license after a professional concurs that I am unable to drive safely, I agree that the following steps may be initiated by \_\_\_\_\_:

he/she may contact my physician so that he/she may alert the state department of motor vehicles, or she/he may do directly.

he/she may take possession of my car keys

he/she may take possession of my car

he/she may sell my car and use the proceeds to pay for alternative transportation.

iii. Include a provision about driving cessation in health care and financial powers of attorney.

### **III. Sometimes The Legal Process Gets in the Way**

Judges and lawyers are no more infallible than are doctors, nurses, social workers and the other professionals involved in caring for the elderly, and planning may not always produce the optimum results. A number of recent cases help shed some light on the importance, value and danger of advance planning for seniors. Though not by any means encyclopedic, these court cases illustrate some of the possibilities and difficulties inherent in the planning process.

A. Guardianship: *Smith v. Lynch*, 821 So.2d 1107 (Florida Court of Appeals, 4<sup>th</sup> District, 2002) stands for the proposition that thoughtful planning can not only obviate the need for court proceedings, but may even prevent the imposition of guardianship. An elderly woman, already suffering from moderate dementia, consulted an attorney and signed a durable power of attorney naming her husband and step-daughter as joint agents. There is some dispute about whether she was truly competent to execute the documents; her attorney believed that she understood the significance of the power of attorney, but her attending physician testified that she would not have been able to

comprehend the documents at the time she signed. A grandniece and grandnephew initiated guardianship proceedings. The probate court, first finding that the woman was incapacitated at least as of the time of the guardianship petition, nonetheless declined to appoint a guardian. The Florida Court of Appeals agreed, ruling that state law requires imposition of the least restrictive appropriate alternative to provide for care of incapacitated adults, and that the power of attorney was adequate to permit family to make decisions for her without the necessity of court involvement. The guardianship petition was denied.

B. Durable Power of Attorney: *Bacon v Donnet* (Ohio 9<sup>th</sup> District Court of Appeals unpublished opinion, March 19, 2003) illustrates how planning documents can be (and frequently are) misused to alter the principal's wishes. Mary Sauerwein had signed wills leaving the bulk of her estate to charity, then to her nephew William Donnet, and finally leaving \$675,000 to her nephew and the remainder of her nearly \$4,000,000 estate to charity. The nephew also held a power of attorney, and after he learned of the final change in her estate plan he used the power of attorney to create a living trust and transfer the bulk of her assets into the trust. The trust left a small amount to two charities and the residue to the nephew/agent; the trust also included a provision that anyone challenging the trust's terms or validity would be automatically and completely disinherited. Ms. Sauerwein then sued to recover her assets from the trust, changed her will yet again—this time to completely disinherit her nephew—and revoked the power of attorney. Although Ms. Sauerwein died before the litigation was concluded, the trial court ultimately ruled that her nephew's actions—regardless of motivation—exceeded his authority under the power of attorney. The Ohio Court of Appeals agreed, and ordered the trust dissolved and the property returned to Ms. Sauerwein's estate. The cost of securing that resolution, and the anxiety occasioned to Ms. Sauerwein before her death, can be imagined but perhaps not quantified.

C. (Lack of) Attorney Duty: *Persinger v. Holst*, 639 N.W.2d 594 (Michigan Court of Appeals, 2002) demonstrates that even when planning does go awry, it may be impossible to pursue a lawyer who failed to anticipate and prevent the problems. Helen Fuite, an elderly widow, consulted with attorney Richard Holst about preparing a power of attorney. In fact, Ms. Fuite was brought to Mr. Holst's office by another of his clients, Mark Hall. Mr. Holst may have been aware that Mark Hall was not a particularly good money manager and even that he was illiterate. In any event, Mr. Hall used the power of attorney he obtained to systematically fleece Ms. Fuite of her assets. When a

conservators was ultimately appointed, the conservator sued attorney Holst for permitting her to sign a power of attorney at all, and particularly for failing to protect her from the incompetence of her chosen agent. The Michigan trial court dismissed the claim, and the Court of Appeals agreed—an attorney has a duty to reasonably determine a client’s competence before permitting the client to sign a power of attorney, said the appellate court, but the attorney has no duty to dissuade a client from making a poor choice in her selection of agent.