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# Long-Term Care Decisions

*Ethical  
and Conceptual  
Dimensions*

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## CHAPTER SEVEN

## Safety and Independence:

## Rethinking Some Basic Concepts in Long-Term Care

Bart J. Collopy

*The Clash of Safety and Independence*

In both institutional and community-based long-term care, concerns about the safety of the frail elderly often clash with concerns about their independence. As both Terrie Wetle (Chap. 4) and Rosalie Kane (Chap. 5) indicated in their earlier discussions of care planning and case management, such clashes are generally resolved in favor of safety. This suggests that, for all the recent attention given to the autonomy of patients, long-term care continues to take a highly protective stance toward the frail elderly—and a highly cautious stance toward the risks that come with their self-determination.

From an historical perspective this is no surprise. In Chapter 2 Martha Holstein and Thomas Cole described the grimly custodial almshouses that were the predecessors of modern long-term care. Twentieth-century reforms brought an end to these institutions chiefly by medicalizing long-term care and bringing dramatic improvement in modes of treatment, professional standards, public image, and government funding (Wilson, Chap. 3). But with these advances came a deep dependence on the medical model of care, a dependence that has kept long-term care ethics in tutelage to acute care ethics.

As a result, questions about the independence of nursing home residents or home care clients are still framed within the logic and ethics of *medical* decision making (Arras, Chap. 10), in terms of what George Agich termed ideal autonomy in the previous chapter. Thus, independence means autonomy, and autonomy means determining one's own medical treatment. Other areas of human independence do not figure

conspicuously in the medical model. Indeed, in the hospital these other areas of independence are routinely curtailed for the sake of immediate medical goals and regimens. In the same fashion, safety also becomes a limited issue, an important value certainly, a presumed condition of the caregiving environment, but hardly a focal point in patient or provider decision making about medical treatment. Even decisions about life-sustaining care are not framed as choices between safe and unsafe care. The patient who chooses palliative over aggressive care is not left "unsafe." In fact, the very language of safety rings oddly here, as if talk relevant to building and equipment standards had intruded into the discourse of clinical ethics.

In long-term care, on the other hand, safety *is* part of the moral vernacular. The extended course of care and its "daily life" aspects do not allow the tight controls that operate in the short-term, episodic world of acute care. When care is provided for long periods of time, within a *living* as well as *treatment* setting, issues of independence reach far beyond the bounds of medical treatment decisions. Moreover, for the elderly the complications of frailty often seed independence with risk. Thus safety becomes an ubiquitous issue—and an especially conflictive one, as the following two cases illustrate. (The names used are fictitious.)

### Two Illustrative Cases

#### CASE 1

Mrs. Marner is an 83-year-old widow, living alone in a small one-bedroom apartment. Until recently her chief medical complaints were arthritis and high blood pressure, but a year ago she fell and broke her hip. After hospitalization, she returned to her apartment and recuperated there with the help of home care services. She now receives fifteen hours per week of assistance from a home care aide and monthly visits from a nurse.

Mrs. Marner's apartment is cluttered with old furniture, piles of newspapers and magazines, collapsing cardboard boxes filled with the belongings of her dead sister. Three cats roam this dusty terrain, their feeding dishes and litter boxes scattered about. The apartment has poorly working appliances. It is hot and airless in summer, poorly heated in winter, often without hot water in any season. Mrs. Marner, fearful of being robbed, rarely ventures outside the apartment. She spends her days sitting quietly in the semidark, "rummaging through the past," as she puts it.

The aide originally assigned by the home care agency found these working conditions intolerable and quickly asked to be removed from the case.

Her replacement is uneasy about the neighborhood and complains that she cannot clean the apartment decently, because Mrs. Marner will not let her move anything. The aide also has problems with Charley, Mrs. Marner's 60-year-old nephew, who is a regular and irksome visitor. Charley complains about the aide's work and gets his aunt to have the aide prepare food that *he* then eats. Ostensibly, he is Mrs. Marner's family caregiver, but as the aide sees it, he just comes around looking for free meals and money. The aide reports that Charley makes out checks that Mrs. Marner signs without reading. According to the aide, Charley "takes his percentage." By month's end, Mrs. Marner is usually low on funds, sometimes reduced to little more than soup and bread. At this point, Charley disappears until next month's social security and pension checks arrive for his aunt.

The nurse who oversees Mrs. Marner's case is concerned about all of this. She is particularly bothered by what she sees as a slide in Mrs. Marner's functional status. In the last six months her arthritis has worsened, and her mobility decreased measurably. Her short-term memory also seems to be failing, and she often forgets to take her blood pressure medication. In general, her earlier self-caring and self-directing capacities have slipped noticeably.

During her monthly visit with Mrs. Marner the nurse suggests that the agency increase the hours of assistance Mrs. Marner receives. And she raises with Mrs. Marner the prospect of nursing home placement. Mrs. Marner abruptly rejects both suggestions. The aide is helpful and friendly enough, Mrs. Marner says, but she likes her privacy, and, besides, the aide doesn't get along with Charley. The nursing home is simply out of the question. "I want to stay in my own place. I've been here for thirty-five years. A nursing home is no place to be."

#### CASE 2

Mr. Rand is a 78-year-old nursing home resident, a diabetic with Parkinson's disease. He has been in the nursing home for six months and during that time has become an increasingly "problematic" resident in the eyes of the staff. He recently began to go barefoot in his room and then into other areas of the home. It is now a daily struggle to get him into shoes and socks. The staff has warned him that he will not be allowed shoeless in the dining room, but he often manages to get to his table without being spotted. Once seated, he is verbally abusive if staff members try to get him back to his room and into shoes.

Apart from the impropriety of a barefoot resident wandering through the home, the nursing staff is afraid that Mr. Rand will sustain some cut or bruise that will develop into a major medical problem. His diabetic condition is quite serious, and he has already had a number of troublesome infections. To complicate matters further, Mr. Rand has decided to stop wearing his hearing aid. His resulting high-decibel speech disturbs other residents, who generally shun him. Staff members find the simplest communication with him onerous. Increasingly isolated, he has become angry and aggressive. So far his aggression has been mainly verbal, but he has intimidated one resident sufficiently to have him ask for a transfer to another floor. Staff members are concerned that Mr. Rand will intimidate other residents or that he will eventually become physically aggressive. In an attempt to deal with these problems, the Director of Nursing asks Mr. Rand if he would be willing to talk to a psychiatrist. He flatly refuses. "I don't want anyone running *my* brain," he says.

#### *Is the Autonomy/Beneficence Framework Sufficient?*

These two cases suggest some of the ways that independence can conflict with safety in long-term care. In both cases, care providers might adopt a waiting strategy, but neither safety nor independence will be well served if protective services must step in and rescue a badly incapacitated Mrs. Marner from her apartment or if Mr. Rand's care providers find themselves treating a resident he has assaulted or a nonhealing foot wound he has dealt himself. On the other hand, Mrs. Marner does not want to leave her apartment or receive more home care assistance, and Mr. Rand is equally adamant about going his own rough way.

In standard bioethical discourse these two cases present "classic" conflicts between autonomy and beneficence. The guiding bioethical consensus about such conflicts holds that the autonomous and informed choices of competent individuals should be respected, even if others consider these choices risky or unwise. Care providers' concern for the well-being of patients ought not become coercive or controlling. Patients should remain free to choose against good advice—indeed to define the very meaning of "good" in personal and idiosyncratic terms, even when this cuts against the common wisdom of family members, individual care providers, or the health care system at large.

But while this ethical analysis keeps providers from forcing treatment on unwilling patients, it offers limited guidance in long-term care where decisions about medical treatment make up only part of auton-

omy's complex terrain and where a "noninterventionist" approach overlooks the supportive and enhancing tasks of chronic care (*Gerontologist*, 1988; Hofland, 1990). In essence, the autonomy/beneficence framework of acute care imposes a decision-making model that is both conceptually and pragmatically narrow, better suited to patients making decisions about specific medical treatments than for residents or clients shaping the ongoing course of their lives in nursing homes and community settings (Agich, 1990, 1993, Chap. 6; Arras, Chap. 10). The acute care model of an isolated agent rationally weighing treatment outcomes does not capture such things as the nature of family involvement, the dynamic, open-ended, vaguely defined, often subsurface choices that characterize long-term care, the ongoing opportunities for the elderly and their care providers to negotiate partial solutions, to *inch* their way along into agreement and understanding (Horowitz, Silverstone, and Reinhardt, 1991; Moody, 1992; Lidz, Fischer, and Arnold, 1992).

Finally, the terminology of choice in long-term care, "independence and "safety," deserves conceptual inspection in its own right rather than quick translation into the standard autonomy/beneficence framework. Such translation grants conceptual hegemony to acute care, suggesting that independence and safety are polar values and that care providers must invariably choose between them. In contrast with this view, I will attempt to show that safety and independence reveal some deep family resemblances, commonalities that can challenge narrow definitions and forced moral choices.

#### *Safety: Calculating Its Moral Force*

In the broad sweep of human history, safety has hardly been a notion to stir speculative theory or stoke revolutions. "To live *safely*" is something of a minimalist's dream, a pale and cautious aspiration when compared with the desire to live freely, or deeply, or passionately. On the other hand, the world is unpredictable and devouring enough to make safety a compelling human goal under certain conditions. In a room suddenly filling with smoke and cries of fire, we are not likely to ruminate on how philosophically narrow a value safety is.

This would suggest two lines of reflection for long-term care. First, safety ought to be understood within the context of other values. In itself, it provides an extremely limited ethical framework. Secondly, an ethically accurate view of safety would require that we look beyond generalities to particular instances. We have to know the *particular* measure

of a harm to know the advantage of being safe from it—or the obligation to protect others from it. In practice, then, safety offers little generalized ethical guidance. It is not a value that automatically overrules the risky choices or behavior of the elderly. Risks have to be weighed in terms of concrete benefits and harms. As a goal of care, safety has to be tested against other goals; care providers' estimates of risk have to be measured against the elderly's own estimates; *potential* harms have to be gauged by solid predictors, not *worst case* scenarios.

In short, safety is not some absolute, always preemptive mandate. It is one value among many, a value whose force shifts and modulates with circumstances, with the goals and motivations of individuals, with their willingness to bear specific burdens, to take on and struggle against specific threats.

### *Medical versus Psychosocial Definitions*

When it comes to deabsolutizing safety in this fashion, the medicalization of long-term care (Estes and Binney, 1989) is a large obstacle. Just as the medical model neglects the social factors in dementia for a tight focus on somatic pathology (Lyman, 1989), so too it fixes on the somatic aspects of safety, overlooking the psychosocial aspects. As a result, some ethically significant questions go unasked: Do concerns for safety and concerns for independence have a common source? Does protecting the elderly from physical harm have a counterpart in protecting them from psychosocial harm? Should harms to mind and spirit count as heavily as bodily harms? Should care providers recognize that safety reaches beyond physical safety?

In Mrs. Marner's case, for example, a psychosocial definition of safety would suggest that her cats, the boxes of her dead sister's belongings, the dirty, poorly equipped, but familiar apartment, even the parasitic companionship of Charley, may be haven and safe harbor to her. And "safe harbor" is no mere figure of speech here. It presses us to think about safety in terms of broad quality-of-life issues, in terms of those things that sustain Mrs. Marner's sense of security, her continuity with the past, and her ability to keep her life from unraveling in the face of frailty. As Agich (Chap. 6) suggested, autonomy should not be viewed simply within the paradigm of clearly defined medical risks and conflicts. In Mrs. Marner's case, the danger of a fall at home has to be weighed against the risks of institutionalization: fractured patterns of living, emotional pain, and social disability. Her physical safety has to be under-

stood in a continuum with other "safeties": the security of familiar routines and places, the mix of order and spontaneity that is her own daily doing, the self-definition and self-esteem that come from enduring roles and relationships, from a sense that she still lives in touch with her past.

These "psychological safeties" do not support the standard polarity between independence and safety. On the contrary, they suggest a basic intertwining in which independence is a primal form of safety, a way to make the world safe for the self, to secure ourselves against the fragmentation, the assorted tyrannies that circumstances, or human systems, or other individuals, even well-intentioned caregivers, might introduce into our lives. Thus, safety is not a matter of physical protection alone. It touches on issues far more foundational to biomedical ethics and especially critical to the development of long-term care ethics.

### *Safety and Suffering*

The chief foundational issue I have in mind here is the issue of suffering, particularly as it has been approached by Eric Cassell (1991a, 1991b). Cassell sees the primary goal of medicine to be the relief of human suffering. And for him this is not some noble sentiment, a high ideal *presumably* beating at the heart of medical practice. On the contrary, he sees relief of suffering as a problematic mandate, a curt reminder that medicine's intense focus on "hard" clinical data often leaves it insensitive to the inner, personal experience of illness and disability. In Cassell's critique, the theme of *patient as person*, that essential configuration voiced two decades ago by Paul Ramsey (1970), still has an indicting edge.

While admitting the success of clinical medicine, Cassell faults it for disregarding suffering—an experience rooted in perceived threats to personal integrity. Suffering arises when the intactness, the inner logic or "hold" of our lives begins to come apart, when we sense we are losing the struggle to prolong into the future the order of our past lives, the integrity of our past selves. For Cassell, suffering is an elusive datum. It does not provide the kind of clinical evidence found in the physical symptoms of disease and illness. To respond to suffering, then, physicians must develop new modes of diagnosis. They must learn to read patients' struggle with the inner disorder and disintegration that illness brings.

Transposed to long-term care and the discussion of safety and independence, Cassell's approach to suffering would require us to look beyond the so-called "hard" data (the risk of injury or some other medical

complication) to the "softer" personal data (the struggle of individuals to protect themselves from psychological and moral threat). From such a perspective, "noncompliance" shows some unusual variation. The elderly who take risks, who reject protective advice and services, for example, may in fact be searching for another form of safety. They may be struggling to keep the security of familiar places and patterns, to protect themselves from dislocation and diminishment, to mark off their own areas of control, just as Agich suggests in his description of *actual* autonomy in the previous chapter.

To the extent that this is so, individuals such as Mrs. Marner and Mr. Rand are pursuing alternate calculations of safety and risk—calculations that count some physical and medical risks of less concern than risks to the inner balance of the self. Such calculations are critical ones in long-term care where patients must come to terms with conditions that cannot be cured, conditions that are not episodic "outside" threats but disabilities lodged permanently within their lives (Jennings, Callahan, and Caplan, 1988). In making their own calculations of safety and risk, patients are trying, then, to fathom the shoals of permanent, often progressive, disability. They are trying to make sense of their suffering. This sense can be elusive, chambered in the patient's self, something that care providers must interpret from clue and indirection. But a willingness to take on such interpretation can give providers a morally expansive context for dealing with issues of safety.

Within this context Mrs. Marner's choices may be seen as attempts to preserve a personal world which she feels is slipping away from her. In a very real sense, then, she *is* concerned about her safety, but in a context where high blood pressure and broken bones are less worrisome than fractures to the self. Realizing this, care providers might be able to voice their own concerns for her physical safety in a way that would be more convincing to her. If this fails, they might at least be able to understand and empathize with her on the path she is charting through her suffering, a path they might regret yet still respect.

The primary question would be, then, not how to keep Mrs. Marner safe in a physical sense, but how to help her deal with the whole range of threats gathering around her. To respond to her in this way, care providers would have to develop what Cassell (1991b) calls an "aesthetic" reading of her suffering. They would have to understand the personal order and harmony she has constructed in her past life and the dissonance she struggles with now. No focus on safety narrowly conceived

will accomplish this; only a deeper kind of interpretation, a "thick description" of the safety she wants, a sense of the "larger opus" of her life will do here (Aumann and Cole, 1991; Lynn, 1991).

### *"Mere Independence" versus a Wider Definition*

If safety is often a narrowly defined, morally thin notion, so too is independence, especially when it is paired off against safety. In its thinnest form, independence can mean little more than staying out of a nursing home. Independence is thus defined by site, and not by the wide range of quality-of-life considerations important to the elderly themselves. So defined, independence is consistent with frail elderly living in isolation, with few formal services, dependent on informal caregivers whose skills, resources—even willingness to help—may be meager. At this point independence has become "*mere* independence": avoiding the nursing home but struggling on in the community with lean possibilities and limited options (Cohen, 1988).

When independence is so meagerly defined, community-based care is left with impoverished notions of autonomy and diminished quality-of-life goals for its clients. Such a definition also suggests that independence is lost in a nursing home, that if it survives at all, it does so "problematically," as an incubator for noncompliance. In this view, independence means "standing alone" or "standing against," cutting oneself off from others or working against their concerns for one's well-being.

But independence need not be construed in such a self-isolating and confrontational fashion. When we become old and frail, we may still want to go our own way, but that will not necessarily mean we are speaking some elemental "no" to care providers and their concerns. Even if our independence brings us to the thin edges of safety, it may be because we want to live in our own homes with the people (and pets) we have known, with familiar furniture and foods, wearing the clothes we want, washing or not washing as it suits us, and going out or staying put as we please. In an institutional setting our independence will be charted with similar preferences: access to a favorite chair, to the telephone, or to a friend two floors away. We will want the freedom to follow our own inner clocks for eating and sleeping and for getting up and moving about. From our perspective, being independent is likely to mean charting our own way through the minute and mundane realities of daily life (Agich, Chap. 6; Kane and Caplan, 1990, 1993). It will hardly mean some Promethean isolation from others, a declaration of freedom from

all the varied ties that inescapably (and supportively) link us to others.

Our perceptions of independence may still, however, not match those of our care providers. A highly medicalized, protectionist, risk-wary model of care may make them focus primarily on the potential harms that independence can bring: injury, poor nutrition, missed medications, disruptive behavior, and poor personal care. And they may well envision the family members and government regulators who will circle fiercely around these harms. From their perspective, our independence may seem a meager counterweight, especially when it seems to be directed at the small-scale stuff of daily life.

Here we confront one of the critical insights in the recent discussion of long-term care ethics. It is precisely in the quotidian choices of life that the elderly secure—or lose—the world as their own. In chronic care, autonomy is more often a matter of negotiating small freedoms than deciding about feeding tubes (Agich, 1993, Chap. 6; McCullough et al., Chap. 11). In dealing with Mr. Rand, for example, the nursing home staff is liable to face continuing standoffs as long as his behavior is interpreted simply as noncompliance. It might be possible, however, to work out some negotiation and accommodation if staff members perceive his behavior as a struggle to maintain the order of his life, to secure himself within this new environment, to mark off his own safe standards in the midst of the institution's enveloping power.

Cutting his own independent path may be the only way Mr. Rand can see himself safe in the nursing home. Realizing this, his care providers might be able to open up some avenues of negotiation with him. They might be able to strike some initial, small-scale pacts about wearing shoes—or a hearing aid. On the other hand, all attempts in this direction might fail. Mr. Rand may prove unreachable, unreasonable, and resistant as stone. Despite their efforts to understand his suffering and struggle, in the end his care providers may still be pressed into a stark choice between his safety and his independence. But then this choice will be informed by these very efforts to gauge his perceptions and motivations. In short, his care providers will have *journeyed* to this final hard choice, not preemptorily begun with it.

### *Safety, Independence, and Decisional Capacity*

The case of Mr. Rand raises one of the most complicating issues in long-term care: the assessment of decisional capacity. If he is indeed unreachable and unreasonable, his care providers face serious questions

about his autonomy. Someone who cannot understand or evaluate a risk cannot responsibly bear its burdens. If Mr. Rand's problematic behavior is complicated by cognitive or judgmental deficit, then his care providers bear special responsibility to ensure his safety and the safety of others.

The principle of care providers' responsibility can be difficult to apply in practice, however, because assessing the mental capacity of the elderly is a difficult and obstacle-ridden undertaking. Historically inherited cultural stereotypes, described earlier by Holstein and Cole in Chapter 2, can cloud these assessments, suggesting that the frail elderly are *in general* incapacitated, *by and large* unable to understand, weigh, and take responsibility for risks. Even when these biases have been carefully checked, assessments remain difficult. Elderly in the latter stages of Alzheimer's disease or comparably devastating conditions may have clearly lost all decisional capacity, but for massive numbers of the elderly decisional capacity is often a varied and shifting reality. In these elderly capacity can fluctuate over time. It can be obscured by poor communication or by asocial and eccentric behavior. Most importantly, it can be present in certain areas of choice and behavior but absent in others.

Assessing capacity requires that care providers identify the fluctuations and specific arenas in an individual's capacity, overcome potential communication barriers, and distinguish eccentricity from deep unreasonableness. This can be a long and time-consuming business, and also a technically imprecise one, because it is an attempt to gauge *moral* agency as distinct from cognitive skills or agency, to decide whether an individual can still formulate and follow goals, appreciate risks, and assume the burdens as well as the benefits of independence. Assessing this complex of abilities means more than measuring general intelligence or information-processing skills. It is a matter of gauging individuals' moral agency, in particular their capacity to calculate the darker aspects of their choices and to take responsibility for the harms their behavior might breed.

In this light the task of assessing decisional capacity can be ethically discomfiting, disarming even. But discomfort, since it can engender caution, is perhaps a better approach to judging someone else's moral agency than overweening confidence. Moreover, even though there is no technical, ethically "safe" way to judge moral agency, the path of caution is not without purpose or process. In this regard, recent explorations of the "values history" (Caplan, 1992; Doukas and McCullough, 1991; Gibson, 1991) can prove helpful to care providers. The values history provides a format for exploring patients' underlying values and

preferences, their sense of reasonable risk, and their own hierarchy of "safeties." As Kane (Chap. 5) and Laurence McCullough and his colleagues (Chap. 11) suggest in this volume, a formal process for inquiring about values gives providers an opportunity to explore with the elderly their own understanding of independence and safety, as well as the priorities which provide the context for their own choices and behavior. In supplying a baseline of information about an individual, a values inventory can aid the process of assessing decisional capacity, particularly by helping providers decide whether a particular risk-laden choice is authentic or unauthentic, reasonable or unreasonable by the individual's own standards.

### *The Regulatory Framework*

Any discussion of the issues of independence and safety in long-term care must take into account the impact of the regulatory system, a system that takes a protective stance toward the elderly and a generally adversarial stance toward their care providers (see Wilson, Chap. 3). In practice, the protection of the elderly produces a much sharper focus on issues of safety than on issues of independence. The recent government regulations on the use of restraints (Collopy, 1992; Evans and Strumpf, 1989) are a good case in point. It can be argued, first of all, that the regulatory system's past emphasis on safety contributed to the practice of using restraints in the first place. The system encouraged a value scheme that elevated safety to a near-absolute value, preferring clear and predictable "outcomes" to the foggier business of balancing concrete instances of safety and independence against each other. Restraints provided an easy-to-use, relatively inexpensive, highly efficient response. Unfortunately, the behavior that restraints "quieted" was often psychologically and socially complex. In effect, the posey vest was a quick technological fix to an intricate ethical problem.

The context for this technological fix was the perceived regulatory mandate that nursing homes should be injury-free, fall-free, disturbance-free environments. Within this context the 1989 Health Care Financing Administration's prohibition on the routine use of restraints struck many care providers as a puzzling turnabout. The regulatory system that had encouraged this practice through its constant stress on safety seemed suddenly to be reversing itself. The puzzlement of providers cannot be attributed solely to some standing opposition to regulations. In the conciseness standard for such mandates, the antirestraint regulations called

for change without creating the kind of explicatory context that would provide understanding and motivation (beyond the threat of regulatory sanction, that is). There was no reexamination of safety as an ethical and legal mandate, no clear indication that the system was refining its basic notions of safety and protection, that it might be willing to allow the elderly (and their care providers) to take on certain risks. Because it provided no well-developed moral and conceptual context, the new regulation left many care providers perplexed about how the counterweights of safety and independence were shifting within the regulatory system.

Because of this perplexity, the reform of restraint practice has had a relatively contained impact. It has not fostered much reflection about the basic definitions of safety and independence operative in long-term care. Nor has it sparked much discussion about the effect of regulation on the ethical categories and decision-making processes of providers. Yet these are critical matters for the evolution of long-term care ethics. Unfortunately, the present inspection and review processes are geared to catch poor performance rather than to explore and develop innovations in care practice (Cooney, 1991). In general, the regulatory system shows little interest in engaging care providers in common reflection on ethical problems (e.g., the conflicts that can develop between safety and independence). Care providers, in turn, tend to view regulation as burdensome and adversarial. They see it as a system sharp-eyed for infractions but slow to develop common moral frameworks or programs to educate long-term care staff (Day and Klein, 1987). The net result is a culture of care that is highly risk-averse.

On the other hand, the "provider industry" is often slow to respond and largely reactive when it comes to ethical issues. Providers have not yet clearly seized the ethics agenda as their own—with the result that the initiative in this area comes largely from regulators and advocates for the elderly. Indeed, when regulators issue broad guidelines, providers are liable to ask for more explicit instructions, as happened when providers recently pressed HCFA to be more specific about the implementation of the Patient Self-Determination Act (Sabatino, 1993). In looking for even more specific instructions, providers were protecting themselves from possible regulatory sanction, but they were also muting their own moral agency, settling for a kind of "cookbook ethics" in which the ethical calculations of care are made by regulators.

Caring for elderly who pursue their own independence, elderly like Mrs. Marner or Mr. Rand, requires that providers develop the kind of



ethical reflection that is not easily cookbooked. Kane's caution in Chapter 5 against "cookie cutter" care plans applies forcefully here. But when providers are fearful of triggering regulatory sanctions at every turn, such reflection withers. Micromanagement by the system's rules, or the system's *perceived* rules, takes the place of care providers' moral agency. Ethical reflection cedes to the strategies of risk management or damage control. Mrs. Marner becomes a "safety problem," Mr. Rand a "behavioral problem." In both cases, keeping the resident or client safe also keeps the provider safe.

Such an approach technologizes ethics, turns it into a strategic tacking through regulations rather than a struggle with moral ambiguity and dilemma. There are few signals that this is about to change. The system is still reluctant to grant much moral discretion to providers. It still tends to reduce ethics to "following the regs," still suggests that the vulnerable elderly's surest protection lies in the letter of the law.

### Conclusion

But the letter of the law often produces a rigid and minimalist kind of protection. It defines safety and independence in narrow terms, sets them off as "natural enemies," and presses providers to choose between them. A central claim of this chapter, indeed of this volume, is that long-term care is better served by thinking and practice that moves beyond such polarized, bunkered definitions and the either/or decision making they generate.

In dealing with the intricacies of independence and safety it is crucial that long-term care adopt an expansive perspective, one that admits the hazards of life, the risks of autonomy, the moral dilemmas inherent in human frailty—and in human caregiving. In this perspective safety and independence make sense in relation to an individual's *many* values and *particular* goals, in terms of a complex self who may very well autonomously subordinate medical goals and physical protections to other personal ends. Thus, care providers must search for the underlying sources of risky behavior in the elderly, must seek to plumb the noncompliant person's suffering, to find some common ground of understanding. Either/or choices between safety and independence represent positions of last resort. The search for shared understanding, for accommodation, and for tolerable even if not perfect solutions comes first. The underpinning for such an approach is, of course, a kind of conceptual largesse, a perspective that would not position safety and independence as fierce

opposites but would see them as values tightly interwoven and mutually illuminating.

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#### IV RETHINKING FAMILY ROLES AND RESPONSIBILITIES