

**RELATIONSHIP, RESPONSIBILITY AND  
COMMITMENT:  
CORNERSTONES FOR AN ETHICS OF LONG  
TERM CARE**

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## Relationship, Responsibility and Commitment: Cornerstones for an Ethics of Long Term Care

*“Tell me of good and evil,” I asked.  
The old Indian replied,  
“Inside of all people is  
a good dog and an evil dog.”  
“Which one wins?” I asked.  
He smiled a smile that only comes  
with old age and wisdom, and said,  
“The one you feed the most.”<sup>1</sup>*

### **I. INTRODUCTION**

#### ***1. Why ethics education?***

In the movie *The Confession* a man kills three hospital staff members whose negligence and lack of caring, he believes, were responsible for the death of his son. His attorney tries to convince him to plead “not guilty by reason of insanity” but the man refuses. He argues that were he to claim he was insane the deaths of the three hospital personnel would be viewed as meaningless acts of random violence. But, he insists, his acts were not meaningless; they were intended as acts of justice for the death of his son. The lawyer asks him think about his wife, who also lost her son and now faces the loss of her husband as well. The man is quiet for a moment. His lawyer, empathizing with his dilemma, says, “It’s hard to do the right thing.” The man replies, “People think it’s hard to do the right thing. It’s not hard to do the right thing; it’s hard to know what the right thing to do is. Once you know what the right thing is, it’s hard *not* to do it.”

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<sup>1</sup> P.B. Kritek. 1994. Negotiating at an Uneven Table: A Practical Approach to Working with Difference and Diversity. San Francisco: Jossey-Bass, Inc., quoting a story told by artist L. Don Mulkey, Galveston, Texas.

Just so, the purpose of the *Competence with Compassion™: Ethical Decision-Making in the Changing Culture of Long Term Care* training program is not to teach long term care providers to do the right thing. Rather, it is to help them as they seek to determine what the right thing is. More specifically, the program will be valuable in the following ways:

1. It provides a process for making team decisions.
2. It establishes a basis for explaining to others how decisions were reached.
3. It permits consistency, reliability, predictability in the process of ethical decision-making.
4. It provides guidance for addressing unfamiliar or challenging care issues and dilemmas.
5. It counterbalances pressures to make the most expedient decision.

## ***2. Competence with Compassion™: Ethical Decision-Making in the Changing Culture of Long Term Care***

*Competence with Compassion™: Ethical Decision-Making in the Changing Culture of Long Term Care*, CARIE's program of ethics education for long term care providers and staff, includes an introduction to ethics, a new framework for identifying, understanding and fulfilling the ethical obligations of long term care, and a five-step process for resolving ethical dilemmas in the provision of care.

Research has suggested that the act of engaging in conversation about ethical issues will by itself improve ethical decision-making. This is because discussions about ethics require us to reflect on our own values, to listen attentively to the (sometimes) differing opinions of others and to be thoughtful in our response. The development of these skills

can be as valuable for advancing the ethical care of clients and residents as is the acquisition of knowledge of specific ethical approaches and processes. Our hope, therefore, is that this program will be used as the impetus for many lively exchanges among long term care administrators and staff about determining and doing the “right” thing.

## **II. What is ethics?**

### **1. Can/Must/Should**

Making care decisions in the context of providing long term care requires addressing the three main components of care decisions: the clinical, the legal and the ethical.

In considering the clinical component we ask ourselves “What *can* we do?” In other words, using good clinical and professional judgment, knowledge and skills, and available resources, what are all the ways in which we can respond to this situation?

Turning to the legal component we ask, “What *must* we do?” In other words, what do applicable statutes, regulations, and case decisions require us to do or prohibit us from doing in this situation? Law establishes a floor for behavior. It describes what our society holds to be the minimally acceptable standard of conduct. If we fall below that standard, society will impose penalties upon us in the form of civil or criminal liability or professional censure. We can say, then, that law is the standard of conduct society will enforce.

The third component is the ethical component. Here we ask, “What *should* we do?” That is, in light of the full range of things that we *can* do (the clinical component), and with awareness of the things that we *must* or *must not* do (the legal component), what is it that we *should* do in response to the situation before us? Ethics explores the options for action

that go beyond the minimum acceptable behavior established by law. In the words of Spike Lee's 1989 movie, it is about what it means to "do the right thing."

## ***2. Ethics is a peculiarly human endeavor***

*"Man's dignity rises from his ability to reason  
and thus choose freely the good in preference  
to evil."*

*--Walter Lippmann  
September 11, 1945*

Ethics, or morality<sup>2</sup> is surely one of humanity's remarkable gifts. Indeed, it sets us apart from other creatures of the earth. The above quotation from Walter Lippmann, the distinguished journalist, is particularly inspiring when one considers the date. It was written less than a month after the end of World War II, certainly a time that caused many to question whether we are indeed essentially good or evil beings. Lippmann reminds us that the ability to think about and to choose to "be good and do right" is the essence of human dignity. Understanding how to make such choices is what ethics is all about.

We humans are the only species on earth with the ability to make thoughtful decisions about how we will act. Other creatures are hardwired to act in specific ways in response to their environment, for example to threats to their survival or territory, to the need to eat, to the urge to procreate. Imagine a big lion with his beautiful mane lying in the shade of a tree at the edge of an African plain. He spies a zebra that has wandered off from the herd. The lion doesn't consider whether he's in the mood for zebra tonight, or if he really would prefer a little bit of gazelle. The lion will go after that zebra because it is his instinct to do exactly that.

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<sup>2</sup> Although the terms "ethics" and "morality" are not precisely synonymous, their meanings are sufficiently similar that the words are used interchangeably in this manual.

Humans, however, are not hardwired to react purely instinctually as the lion does. Instead, as human beings we can decide what we want for dinner. More significantly, we can deliberate and choose how we will act, what kind of person we want to be, what kind of life we want to live. It is because we can make choices that we simultaneously experience the remarkable freedom of being able to ask and the burden of having to answer the question, “What *should* I do?” The study of ethics offers us guidance as we try to answer this question.

Now, the question “What should I do?” does not always call for an ethical judgment. For example, I might ask “Should I take my umbrella with me today?” or “Should I buy these shoes now or wait until they go on sale?” These questions call for answers based upon *prudence* rather than *ethics*. They call upon us to determine the most effective way to achieve a goal or satisfy a desire. Ethics is different from prudence. It is concerned with determining what it means to be a good person, to do the right thing, and live a good life.<sup>3</sup>

### 3. *Ethical action requires choice*

To ask questions such as “What should I do?” assumes that you in fact have a choice. It simply makes no sense to say that you “should” do something that it is not possible for you to do. In ethics, this is summed up in the maxim “ought implies can”. In other words, to say that one ought to do *X* implies that it is possible for that person to do *X* and, conversely, to say that one ought not do something assumes that he or she can choose

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<sup>3</sup> Although historically ethics has been concerned with the impact of actions and/or choices on other *human beings*, a considerable amount of current ethical thought has focused on the effects of our actions on *sentient beings* (that is, creatures than can feel pain, such as animals,) and on living organisms (e.g., environmental ethics).

not to do it. For this reason, accidents and coerced acts are generally not regarded as morally wrong.

Let's look at several examples of how we experience this in our everyday lives. A person with Tourette's Syndrome compulsively says something racially or sexually offensive. Even if shocked, we generally would not make a moral judgment about him and might even feel compassion for him because we know that he can't help himself. Likewise, we would not "blame" a driver whose car skid on ice in the same way we would "blame" a driver who was distracted by talking on her cell phone even if both situations resulted in fender benders.

The same holds true in health care. Consider the case of Mrs. Gilbert, an 81-year old woman who has been diagnosed with a small cell carcinoma of the lung that has widely metastasized throughout her brain. She also suffers with chronic obstructive pulmonary disease, congestive heart failure and compromised renal function. "Should we cure Mrs. Gilbert?" is not an ethically meaningful question because, very simply, we cannot do it. On the other hand asking, "Should I provide treatments to extend Mrs. Gilbert's life two months?" may indeed have ethical significance in that it very well may be possible to do that.

Again, the same rule of thumb holds true in the context of long term care. If we were to find a male care recipient suffering from dementia in the bed of a female care recipient with dementia who lacked capacity to consent to such a relationship, we would recognize that we have a responsibility to protect her, but would not make the same moral judgment about him as we would of a male employee found in bed with her. We would

understand that the male care recipient might not have the same ability to exercise choice (and control) over his behavior as the employee.

Having a realistic appreciation of what you *can* do (or can avoid doing) is an essential part of the process of deciding what you *should* (or should not) do. But just because we can do something doesn't tell us whether we should do it. So how can we know, out of the entire array of things that we can do, what we should do? In other words, how can we make ethical choices?

We learn morals from a variety of sources from the time we are very young. Most often our moral education begins at home with our parents. It continues through our school and religious teachers. As children we even learn about ethics from our playmates. Think, for example, about a time you or someone else tried to cheat at a schoolyard game and how quickly it was made plain that cheating is wrong!

Although by the time we become adults we seem most often to intuitively know and do the "right" thing, throughout our lives addressing complex problems requires us to reflect upon our moral values and how they apply to situations we confront. Philosophers and theologians have been engaged in this sort of reflection for thousands of years. Their conceptual formulations for deciding what is "good" or "right" continue to provide guidance for us today. Modern thinkers continue to consider these issues and to respond to them in ways that reflect modern day concerns. To give a sense of the wide variety of ways in which ethical issues may be considered, we will briefly describe several prominent approaches to thinking about ethics

#### 4. *Three traditional approaches to ethics*

##### a. *Be a good person*

One way to approach ethics is to focus on the kind of person we should *be*. In virtue ethics, the name given to this approach, the ethical focus is on the qualities of character displayed by the person who is the actor (e.g., compassion, honesty, wisdom, fairness, integrity, courage, generosity) rather than with evaluating the rightness of the action being performed. Of course, our character is given expression in how we act. In other words, what we decide to do is a reflection of who we are, of our values, of our character. In virtue ethics, however, the focus remains on the development of a good character rather than on determining right or wrong actions, *per se*.

We come to understand what qualities are to be valued through the transmission of stories and myths, both religious and secular, and by the examples set by the heroes our society celebrates. Thus we read and hear and learn from stories of the compassion of Mother Theresa in her care for the dying, of the bravery of Davy Crockett's stand at the Alamo, of "Honest Abe" Lincoln's walking miles to return a penny, of Horatio Alger's gumption in "pulling himself up by his bootstraps".

Two prominent advocates of the virtue ethics approach in health care have been Edmund Pellegrino, MD, a cardiologist and former head of the Kennedy Institute of Ethics at Georgetown University and David Thomasma, PhD, former Professor of Medical Ethics at the Neiswanger Institute for Bioethics and Health Policy at Loyola University, Chicago. Pellegrino and Thomasma co-authored a book focusing on the qualities they believed essential to being a good doctor.<sup>4</sup>

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<sup>4</sup> E.D. Pellegrino and D.,C.Thomasma. 1993. *The Virtues in Medical Practice*. New York: Oxford University Press.

b. *Obey the rules*

Another way of thinking about ethics is to believe that what we should do is to follow rules of right conduct. Our earliest moral lessons most often take the form of rules such as “share with your sister”, “tell the truth”, “don’t hit” or “don’t take what doesn’t belong to you”. In contrast to virtue ethics with its attention to the personal character of the actor, rule-based ethics focuses on our actions themselves and whether they conform to accepted moral rules. Much of religiously based morality is rule-based (the Ten Commandments and the Golden Rule are but two obvious examples), as are professional codes of ethics.

One of the best known and most widely accepted approaches to medical ethics establishes four principles for ethical medical practice: Beneficence (doing good); nonmaleficence (refraining from doing harm); respect for autonomy (respecting self-determination); and justice (allocating resources fairly). Practitioners have in turn used these principles as the foundation for rules for making treatment decisions: (1) Do what is in the patient’s best interest; (2) Do no harm; (3) Respect the patient’s decisions; and (4) Minimize discrepancies in healthcare based upon racial, ethnic, cultural or economic factors.

c. *Consider the consequences*

Another traditional way of thinking about ethics is to regard acts as right or wrong solely based upon the goodness or badness of their actual consequences, where goodness and badness are judged in terms of human welfare. According to this view, called *consequentialism*, the goal of moral behavior is to maximize human well-being. To determine what you should do in a particular situation you would consider the

consequences of each of the alternative ways of acting in that situation, the impact of each alternative on all those who will be affected by it, and then select the alternative that would result in the greatest net increase or smallest net decrease<sup>5</sup> in the sum of human well-being. For consequentialists, the quality of the act itself is not what matters. Indeed, acts that we might consider very offensive could be “right” if they result in a net increase in the happiness or sense of well-being of those affected by them.

Dr. Kevorkian presents a well-publicized example of the consequentialist approach to ethics. From all available accounts it appears that everyone involved in his euthanizing of a patient, the case that resulted in his imprisonment, agreed that it was what was best for and desired by the patient. Even in the most critical accounts of his practice there seems to be no suggestion that his actions were anything but solicited and welcomed by both the patient and his family. The patient’s family and Dr. Kevorkian himself believed, and still believe, what he did was therefore the right thing to do. Nonetheless, despite the fact that the patient was suffering greatly and therefore sought his death as a release from a life he no longer wished to endure, Dr. Kevorkian was convicted of a crime and imprisoned because we as a society believe that it is wrong for a physician to act to cause the death of a patient regardless of the consequential good it might do.

Virtue ethics, rule-based ethics and consequentialist ethics have been practiced, written about and debated for centuries. They continue to hold a prominent place in any discussion of ethical reasoning. In recent years, however, new concerns have led to a renewed interest in ethical thought and new ways of understanding our moral obligations.

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<sup>5</sup> The term “net increase” refers to the result of subtracting an act’s negative effects on human welfare from its positive effects. “Net decrease” refers to the situation where the negative impact of an act exceeds its positive impact.

## 5. *Modern Ethical Approaches*

### a. *Ethics as community values*

We have all probably been made aware by our own personal experience and through our reading and education that what is considered right conduct in one community may be different from what is considered right in another community. Indeed, the common belief that the “anything goes” attitude of people living California, New York, or Washington, D.C. is shocking to more conservative moral values of the American heartland is the basis for much American humor. However, moral values, *per se*, may not differ from community to community as much as initially appears; rather what differs is how those values are interpreted and practiced.

Communities establish their own expectations for behavior in small, everyday ways. In the aftermath of a natural or other disaster, newspapers regularly carry feature stories of how the folks in one small town or city got together and pitched in to help rebuild their neighbor’s home or business, brought food and comfort to the victims, raised money to help the stricken. We are reminded through interviews with those involved in the clean up or in the rescue operation that helping a neighbor in need is an expectation of community membership. We also are aware that in large cities there is a greater expectation that such work will be done by “professionals”, whether from governmental, nongovernmental or private agencies. The community as a whole does not seem to believe that any particular individual has a moral obligation to roll up his sleeves and pitch in.

In long term care, too, different communities may hold different moral values or different understandings of how moral values are fulfilled. In some long term care facilities, tube-feeding those residents who cannot accept food orally may be regarded as

obligatory. In other facilities, it may not. Similarly, different home healthcare agencies may have different policies regarding complying with the demands of eccentric clients based upon their particular understandings of their responsibilities as home health providers.

Ethics as community values is premised upon consensus. Assuming thoughtful reflection by community members, it asks, “What do *we* believe is the right thing to do?” Conclusions about ethical obligations may be reached using any of a number of approaches to ethics including the three traditional approaches described above. Those who choose to join a moral community (that is, a community of people who share ethical values and understandings of the application of those values) do so in an informed way, aware of the values held and espoused by the community.

Ethics based upon community values makes possible a pluralistic approach to long term caregiving, allowing those with similar ethical views to create a hospitable environment for exercising their responsibilities to residents or clients. Likewise, it makes choice available to consumers of long term care. By choosing among care providers that reflect a variety of ethical approaches, recipients of long term care can feel more secure that care decisions or choices will be made that are consistent with their own held moral values.

*b. Care Ethics*

“Only connect!”

-- E.M. Forster  
*Howard's End*<sup>6</sup>

In the 1970's, Lawrence Kohlberg, a Harvard psychologist, published the results of a twenty-year study following boys' moral development from childhood through to

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<sup>6</sup> E.M.Forster. 1910. *Howard's End*. London: Edward Arnold.

adulthood. He identified six levels of moral development, starting with moral decision-making based upon reward and punishment (the early childhood or “pre-conventional” stage) through moral decision-making based upon concern for how one is thought of by one’s peers and concern for the well-being of one’s group and its members (adolescence, or the “conventional” stage) through to moral decision-making based upon internalized ethical principles and a personal “moral compass” (adulthood, or the “post-conventional” stage).

Carol Gilligan, a research assistant of Kohlberg’s, became interested in exploring moral decision-making around the issue of abortion following the United States Supreme Court’s 1973 decision in *Roe v. Wade* upholding a woman’s right to abortion during the first trimester of pregnancy. She began to study how girls and women made the decision to have or not have an abortion. Applying Kohlberg’s stages, Gilligan found that her subjects tended to cluster at the conventional stage of moral decision-making; that is, their decisions reflected a deep concern for how they would be thought of by and how their decision would affect those other persons whom they cared about including, for example, the father, the potential child, their friends and family members. Her research results seemed to indicate one of two possibilities: Either girls and women tend not reach full moral maturity (Kohlberg’s adult stage), or girls’ and women’s ways of making ethical decisions were simply different than men’s.

In her book based upon her own research,<sup>7</sup> Gilligan argued that while the stages posited by Kohlberg might be true for boys and men who were his research subjects they could not be assumed to be universally true. She hypothesized that because women traditionally have spent their lives within the home and family caring for and about others

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<sup>7</sup> C.Gilligan. 1982. *In a Different Voice: Psychological Theory and Women’s Development*. Cambridge, Mass.: Harvard University Press.

with whom they are in close personal relationships, including those dependent upon them such as young children, the elderly, and the sick, rather than in the public worlds of business and politics, they have developed an understanding of moral action as responsive to commitments of particular caring relationships. In other words, men had developed a framework for ethics that made sense within the world that they traveled most, the world of arm's length transactions with relative strangers who were often competitors or adversaries. Gilligan suggested that women's traditionally very different life role had led them to develop a moral framework more focused on the needs and feelings of cared-for others. She suggested that Kohlberg's stages might accurately describe male moral development but not human moral development.

Gilligan's work led to a sea change in thinking about ethics. Previously, moral obligations were generally regarded as universal and impartial. They were universal because they applied identically to everyone in identical circumstances; they were impartial because they were irrespective of the relationship (if any) between the persons involved. In other words, one's duty to be honest and to tell the truth in a particular situation would be determined without regard to whether the person to whom you were speaking was a stranger or your mother, and that duty would apply to anyone and everyone else under the same set of facts.

Gilligan's approach to ethics has been given the name "care ethics". The basic and path-breaking premise of care ethics is that rather than being an individualistic endeavor of lone decision-makers (think of Rodin's famous statue, *The Thinker*), ethics begins in relationships. Ethical problems arise and choices must be made within the context of *particular* relationships and ethical conduct consists in responding with care to another

with whom we are in relationship. Care ethics assumes and accepts that membership in family and community involves the exchange of some degree of individual autonomy in favor of some level of cooperation in the interest of the well-being of each and all and sees value in such a trade-off.

This corresponds to our own actual experience. We understand that our ethical obligations are shaped by the nature of particular relationships and the people with whom we share those relationships. For example, take the obligation to tell the truth. Many if not most of us might agree that our obligation to tell the truth to a stranger regarding our whereabouts on a particular evening is different from our obligation to tell the truth to our spouse. Our obligation to tell the truth might also differ depending upon the subject matter and the particular other person involved. For example, we might not have the same obligation to tell the truth to a person who could not absorb or understand it (e.g., a child) as we might to a person with full comprehension of its significance. To some extent, then, the nature of our relationship with another person gives shape to our moral obligations to him or her.

Whereas implicit in traditional approaches to ethics is the presumption that ethical decision-makers are totally rational and free individuals, independent of personal relationships and larger social forces, care ethics reflects our experience of moral decision-making as being embedded in, responsive to and influenced by interpersonal commitments including friendship, love, and caregiving. It implicitly, if not explicitly, recognizes the difficulties presented by conflicts that arise among these commitments and between our commitments and our personal wishes and goals. Indeed, what the traditional approaches with their assumptions of individualistic and rational deciders and actors exclude is

precisely what most of us would regard as most valuable and most important to emphasize when thinking about our moral obligations. Care ethicists require that ethics take account of experiences of interdependency and of the nature of and concerns within intimate relationships.

### ***6. The Ethics of Responsibility: An Ethical Model for Long Term Care***

While care ethics sets out a vivid conceptual foundation for an ethics of personal relationships, it does not seem quite adequate to capturing the ethical issues of the *professional* caring relationship. Although personal caring relationships may develop between caregiver and care receiver in the course of providing long term care, one of the essential and distinctive features of long term care is the (professional) obligation to care regardless of one's personal feelings. Moreover, the "caring for" that reasonably may be asked of and reasonably may be expected from long term care practitioners has boundaries. It is defined by job descriptions, terms and conditions of employment, and responsibilities to others with equal moral claim on the caregiver's time and attention. If asked to bathe a care recipient, for example, a charge nurse might say, "That's not my job" and she might very well be right, at least so far as her job description is concerned. At shift's end, a nurse aide is *entitled* to leave even though a resident in distress pleads for him to stay. A home care aide may need to leave a client to complete her visits for the day even though she knows the client will be alone, and lonely, for the rest of the night.

Margaret Urban Walker offers an understanding of ethics that seems to most fully capture the nature of ethical obligations in the context of long term care. Walker proposes an "ethics of responsibility".<sup>8</sup> According to Walker, we are responsible to those who are

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<sup>8</sup> M.U.Walker. 1998. *Moral Understandings: A Feminist Study in Ethics*. New York: Routledge.

vulnerable to our actions. The vulnerability that creates responsibility in another may arise in any of three ways. The first way is through the nature of the relationship itself.

Relationships such as those of parent and child, of husband and wife, of friends and partners create mutual vulnerabilities through the feelings of love, trust, and dependence that they give rise to and that are part of their very nature. By entering into and remaining within such a relationship we create in the other a legitimate claim upon us. We become responsible *in some way* to the other in whom we have implicitly allowed such feelings to develop.

The second way in which we may become vulnerable to another is by making explicit representations about ourselves and our intentions that another is permitted or encouraged to rely upon. If we expressly tell someone that she can count on us in a particular way, we have made her vulnerable to our carrying through on our representation. We therefore have a responsibility to her to do or be as we have said.

One person also can be made vulnerable to another in a way that creates corresponding responsibilities in the other through the extreme plight of the one and the unique ability or proximity of the other to provide assistance. Thus we recognize the moral responsibility of an adult who is able to swim to save a drowning child, even if that child is a stranger to him.

Walker's ethics of responsibility offers an effective model for understanding the ethical obligations of long term care. The very nature of the relationship of caregiver/care receiver is one giving rise to reliance and trust in the care receiver. "I will take care of you" is the implicit pledge of one holding him- or herself out as a long term care provider or

practitioner. In so doing, one has invited the vulnerability of the care recipient and assumed the responsibility that is the moral response.

Such responsibility is called forth not only by the implicit nature of the caregiving relationship but also by the express statements made to the care recipients entering into it. Care providers encourage care consumers to engage them as caregivers by describing the quality and kinds of care they will provide. Consumers make choices about whom they will entrust with the care of themselves or their loved ones based upon these representations. Such express representations are the basis for an understanding between care giver and care receiver by which long term care providers become responsible to those who are dependent upon them for their fulfillment.

Walker's ethics of responsibility is a comprehensive and useful way to conceptualize and discuss the ethics of long term care because it takes account of not only the vulnerability of the care recipient but also of the fact that particular moral obligations may be established by and respond to specific social contexts such as professional caregiving. It provides the theoretical foundation for the model of long term care ethics CARIE has developed and which is described below.

### ***7. Ethical Orientations***

The above varieties of ways of "doing" ethics have led ethicists to speak of two *orientations* to ethics that offer alternative over-arching ethical visions. The *justice orientation* emphasizes fairness and equal treatment. Its emphasis is on refraining from doing harm or interfering with another person's pursuit of happiness rather than on acting in behalf of another. The *care orientation*, on the other hand, understands moral obligations to include promoting the well-being and interests of particular other persons with whom we

are in relationship rather than treating everyone equally and merely refraining from interfering with such well-being and interests.

The traditional approaches to ethics (i.e., be a good person, obey the rules, consider the consequences) reflect the justice orientation. They are presumed to be universal and impartial: “Universal” because they are to be applied to everyone in like circumstances, “impartial” because they apply regardless of any particular characteristics, circumstances, or relationship between the persons involved. Philosopher Thomas Nagel has written that those who make moral judgments from the justice orientation are expressing a “view from nowhere”<sup>9</sup>; that is, they are the judgments of one who is not situated in any particular set of circumstances. Whereas the justice orientation conceives of morality in terms of fairness and ties ethical decisions to the understanding of rights and rules, the care orientation understands morality as arising from the recognition of relationship and the responsibilities that attend relationship.<sup>10</sup>

The difference between the justice and the care orientations is illustrated by the following example. Imagine you are aboard a boat out for a harbor cruise. Suddenly the boat starts taking on water and soon it is sinking. All those aboard are tossed out into the sea. You grabbed the inflatable rubber dingy as you went overboard. To your right you see three individuals you met on the ship, whom you know to be scientists close to finding a cure for cancer, thrashing about; to your right your own daughter is crying for help. You know that in the choppy sea you will not have time to save both the scientists and your daughter. From the justice orientation the ethical decision-maker in this scenario is a generic individual. His or her particular life relationships, ties, and affinities are of no

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<sup>9</sup> T.Nagel. 1989. *The View From Nowhere*. New York: Oxford University Press.

<sup>10</sup> Gilligan., *supra* n. 7, pp. 18-19.

moral consequence. Thus a consequentialist (justice orientation) would likely tell you that the right thing to do is to save the three scientists who will cure cancer over the one young girl (the greatest good for the greatest number). A care ethicist would give moral weight to the special bonds of love, commitment, vulnerability and responsibility that exist in the relationship between a parent and child.

An ancient story tells of a man who was walking along the road when he saw an animal in the distance. He continued walking and as he got closer to the figure he realized that it was not an animal but another man. He continued along the road and, as he got closer still, he realized that the figure walking toward him was not just another man but his own brother. Ethical approaches from the “justice orientation” take the view from the distance, where what we see are the generalized commonalities among people and situations. Moral decision-making from the care orientation takes an “up-close and personal” view, where we become more aware of distinctions among individuals, of the particular features of persons and their situations. Retelling the above story in the context of long term care relationships with clients and residents, we recognize before us first a human being; then, as we move closer in, we see a person with infirmities, in need of long term care. As we move closer still, we see Mrs. Jones or Mr. Smith, an individual with a particular life story, particular needs, and particular ways of navigating through her/his days.

Neither orientation fully captures the ethical concerns of long term care; indeed, ethical practice in long term care incorporates aspects of both orientations. It requires fairness and attention to the quality of care for all residents and clients *as residents and clients* as well as responsiveness to the well-being and interests of each particular client or

resident. Moreover, while the values of responsiveness and relationship that are the hallmarks of care ethics ideally are also the essence of long term care, individual providers' obligations are not open-ended but are professionally and contractually defined. Staff positions are subject to terms of employment (e.g., hours, job descriptions) that establish and limit a care provider's obligations to recipients of care and also establish what the care provider is entitled to in return (e.g., salary, benefits). In contrast to *personal* caring relationships, long term care providers have responsibilities to residents and clients to continue providing quality care even where caring impulses or feelings of connection do not arise.

### **III. Developing an ethics of long term care**

#### **1. *Renewed interest in medical ethics***

In our everyday lives none of us practices purely virtue ethics or rule-based ethics or consequentialist ethics or even care ethics. Rather, we call upon one or another of these approaches as seems appropriate or useful for figuring out the right way to act in a particular situation. We try to be virtuous, we try to follow the rules of right conduct, we try to figure out what will result in the best for everybody, and we try to respond to the needs of those whom we care about and to fulfill our responsibilities to them. We have a fund of knowledge of ethics and an array of ways of being ethical that have been transmitted to us by parents, teachers, and our life experience, that we can call on almost automatically to address everyday situations.

Sometimes circumstances challenge our ethical understandings. For example, we might confront a situation we have not encountered before for which we have no experience to draw on. Or it may be a situation that challenges deeply held values or that

brings those values into conflict with one another. Our personal values may be called into question by changes in the society around us. In these circumstances we may not be able to rely on intuition or what we have been taught in order to know what we should do or how we should be. It was for just such reasons that medical ethics began attracting so much attention about thirty or forty years ago.

Of course concern with medical ethics goes back thousands of years. The Hippocratic Oath, dating back to ancient Greece, has been a foundation of Western medical ethics since the Middle Ages. The Oath prohibits the physician from participating in euthanasia or abortion and from engaging in sexual relations with his patients, while requiring him to preserve confidentiality and privacy, protect patients from harm and injustice, and uphold the honor and traditions of the medical profession. While other authoritative statements of medical ethics have been developed over the centuries,<sup>11</sup> the Hippocratic Oath has remained a foundational statement of medical ethics into the 20<sup>th</sup> century and even today is administered in many medical schools to medical students as they embark on their clinical years.

Changes both inside and outside the world of medicine during the second half of the 20<sup>th</sup> century have led to an intensified focus on the ethics of medical practice and research. First, tremendous scientific and technological developments in medical practice itself raised ethical issues. For example, the development of new surgical techniques and anesthesia to treat the injured during World War II, of more sophisticated respiratory support in response to the polio epidemics of the mid-1900's, and of chemotherapy and

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<sup>11</sup> See, e.g., Thomas Percival's *Medical Ethics or a Code of Institutes and Precepts Adapted to the Professional Conduct of Physicians and Surgeons*, published in 1803; the American Medical Society Code of Ethics developed in the late 19<sup>th</sup> century and revised regularly since then; and the ethical codes of the boards and colleges of specific medical specialties.

radiation therapy in the 1950's for the treatment of cancer made it possible for individuals to survive injuries and diseases that previously would have been fatal. However, survival sometimes raised questions of the proper ends of medicine. Then, in the early 1960's, the formation of committees, dubbed "God Committees" by the press, charged with deciding who would be given access to newly-invented and scarce kidney dialysis machines, caused public outcry when the criteria that these committees developed reflected judgments about the value of particular lives.

An article on abuses in medical research published by Henry Beecher, a respected Harvard Medical School professor, in the *New England Journal of Medicine* in 1966<sup>12</sup> raised additional alarm about the state of medical ethics. Beecher exposed twenty medical research experiments conducted at the nation's leading medical research institutions in which investigators endangered the life or health of their subjects without informing them of the risks of the research or without obtaining their consent to be research subjects. These research investigations included withholding a proven treatment to test the efficacy of an experimental treatment; injecting live cancer cells into elderly men to study immunity to cancer; and intentionally exposing children who were residents at a facility for mentally ill and retarded children to the Hepatitis B virus to try to develop a cure. To understand the impact of Beecher's article it is important to keep in mind that it followed by less than twenty years the full revelation of the Nazi doctor experiments that horrified the consciences of people around the world.

Factors beyond the practice of medicine itself also contributed to the intensified interest in medical ethics. The traditional image of the physician as the wise and benevolent

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<sup>12</sup> H.K.Beecher. 1966. "Ethics and clinical research". *New England Journal of Medicine*, 274, 1354-60.

father whose judgment is beyond question was forever changed as a result of social, legal and political forces that erupted in the 1960's and 1970's. The civil rights, anti-war and women's movements challenged traditional ideas of authority and emphasized individual rights and power. It was not long before the impact of these social forces affected the belief in the omniscient and omnipotent doctor. In 1971, the Boston Women's Health Collective published Our Bodies, Ourselves, expressly challenging the presumption that doctors are properly vested with authority to make medical care decisions for patients. By encouraging and empowering women to take back control of their own health care from their physicians, Our Bodies, Ourselves was instrumental in changing the role of the patient from passive to active participant in her/his own medical care.

The legal system also became a key player in the increased attention to medical ethics. In the opinion in the Karen Ann Quinlan<sup>13</sup> case in 1976, the New Jersey Supreme Court judge hearing the case expressed his belief that the courts are not appropriate places for addressing the end of life decision-making issues that the Quinlan case raised and suggested for the first time in such a formal setting that hospital ethics committees should be formed for that purpose. The notoriety of the Quinlan case and the press coverage it received gave the idea of hospital ethics committees great currency and advanced the notion that questions of appropriate medical care were not always legal in nature but rather might raise ethical issues that needed to be addressed by those with the education, experience and skill to reflect upon and resolve them.

Recognition of the heightened concern with medical ethics also came from the political realm. In the mid-1970's, in no small part as a response to Professor Beecher's article on research abuses, Congress created the National Commission for the Protection of

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<sup>13</sup> Matter of Quinlan, 70 N.J. 10 (1976)

Human Subjects of Biomedical and Behavioral Research. Its members were charged with drawing up regulations that would protect the rights and interests of subjects of research.<sup>14</sup>

The National Commission issued a number of reports, perhaps the most famous of which was the Belmont Report setting forth three ethical principles for medical research:

- Respect for persons (individuals should be treated as autonomous agents, and persons with diminished capacity are entitled to protection)
- Beneficence (the possible benefits, i.e., therapeutic value, of research should be maximized and the burdens minimized for the subject)
- Justice (the benefits and burdens of research should be fairly distributed among individuals and populations)

The developments in research ethics combined with technological and scientific advances and social and demographic changes led to the reconsideration not only of the ethics of medical research but the ethics of clinical medical practice as well. The principles set forth in the Belmont Report became the basis for a broader discussion of ethics in medicine contained in what is arguably the most influential book on modern medical ethics to date.<sup>15</sup> The ethical framework described in Principles of Biomedical Ethics has emerged as the leading paradigm for medical ethics around the world. It does, however, have its

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<sup>14</sup> The National Commission was followed in the mid-1980's by the creation of the President's Commission for the Study of Ethics in Medicine and in Biomedical and Behavioral Research. Today there exists the National Bioethics Advisory Committee, whose members are appointed by the President.

<sup>15</sup> T.L.Beauchamp and J.F.Childress. 1979. *Principles of Biomedical Ethics*. New York: Oxford University Press. The principle of "respect for persons" in the Belmont Report was changed to "respect for autonomy" in the *Principles*; Beauchamp and Childress also added a fourth principle, "nonmaleficence", or do not harm. The book is currently in its 5<sup>th</sup> edition.

critics, two of whom gave the name “principlism” to the Beauchamp and Childress framework<sup>16</sup>, a name that has since been widely adopted by supporters and detractors of the approach it describes.

The emphasis that Principles of Biomedical Ethics placed on respect for autonomy has had a profound effect on the practice of long term care. The federal Omnibus Budget Reconciliation Act of 1987 picked up the language of autonomy in regard to ethical long term care practice, in part perhaps based on the classic status already accorded the Beauchamp and Childress book. Some have argued that the emphasis on autonomy in ethics, while no doubt articulating a legitimate concern in health care, has drowned out other valid and valuable issues of care.<sup>17</sup>

## ***2. A New Ethics for a Changing Vision of Long Term Care***

Hospitals and nursing homes share an early history as “places of last resort”. As recently as the late 19<sup>th</sup> and early 20<sup>th</sup> centuries, the sick with family and/or resources were cared for at home. Only the poor and alone went to hospitals that were, for the most part, maintained as charitable institutions. For their part, nursing homes are the descendants of the old alms houses, or “county homes” which, like hospitals, provided care for the poor and abandoned.

As science contributed to medical advances, hospitals became more attractive. Antisepsis reduced the health threat of contagion posed by a hospital stay. Medical and

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<sup>16</sup> K.D.Clouser and B.Gert. 1990. “A critique of principlism”. *Journal of Medicine and Philosophy*, 15, 219-236.

<sup>17</sup> See, e.g., M.Slote. 2007. *The Ethics of Care and Empathy*. New York: Routledge; M.A.Fineman. 2004. *The Autonomy Myth: A Theory of Dependency*. New York: The New Press; W.Gaylin and B.Jennings. 2003. *The Perversion of Autonomy: Coercion and Constraints in a Liberal Society* (Revised and expanded). Washington, D.C.: Georgetown University Press; J.Kultgen. 1995. *Autonomy & Intervention*. New York: Oxford University Press.

surgical advances could better be provided in hospitals. Thus, hospitals began to be looked upon as places where cure was more possible than at home. As more and more people sought to be cared for in hospitals, the stigma associated with being a hospital patient diminished.

Nursing homes did not share in the image improvement that science afforded hospitals. Into the 1960's, in the public's mind at least, the nursing home remained as it had been: A place for those with neither home nor money nor loving family members or friends to take them in. The county homes offered "three hots and a cot", providing food and shelter for those unable to care for themselves and with no one else to care for them. This may be called the "custodial model" of long term care.

Changes in Medicare rules drove changes in long term care in the 1960's. Nursing homes became "skilled nursing facilities" in order to qualify for Medicare reimbursement. The evolution to the "medical model" thus was driven by essentially bottom line concerns. The shift from the custodial model to the medical model for long term care constituted a first "culture change" movement. The medical model has now been recognized as an inadequate and inappropriate approach to providing long term care. While efficient and effective for receiving medical care, the medical model offers a limited and unsatisfying way to live one's life.

Dissatisfaction with the medical model has led to efforts to once again introduce culture change into long term care. Alternatively referred to as "person-centered", "consumer driven", "hospitality", "social", "autonomy-based" "Greenhouse™, or Eden Alternative™, the new models all share an understanding of the limitations of the medical model that has characterized long term care for the past forty years. The move away from

the medical model has called for a reconsideration of the ethical obligations of long term care providers. *Competence with Compassion™: Ethical Decision-Making in the Changing Culture of Long Term Care* offers such a new understanding.

### ***3. A commitments-based ethical framework for long term care***

Before introducing you to CARIE's new framework for long term care ethics it will be helpful to place ethics within the context of long term care decision-making. Ethics is not the only thing you need to consider when facing a care decision. Good care decisions require that appropriate thought be given to clinical choices and to applicable legal requirements as well. These three areas, clinical practice, law and ethics are behind the three basic questions mentioned earlier that need to be answered before any care decision is made: What can I do? What must I do? What should I do?

The first question, "What can I do?" is the *clinical practice* question. Another way of stating this is to ask, "Applying clinical and professional skills and judgment, and using the resources available to me, what are all the possible ways in which I can respond to this care issue?"

The second question, "What must I do?" is the *legal* question. It seeks to determine the conduct or response that society as a whole has decided to enforce through its laws and regulations as a minimum standard of conduct. Fall below this standard and you will be penalized through civil liability and fines, professional censure or, in the worst case, criminal penalties.

The third question, "What should I do?" is the *ethical* question. In other words, given all the possibilities for action available to me in this situation (all the things I *can* do)

and mindful of the applicable laws and regulations (those things I *must* do or not do), which among the available options for action *should* I take?

All three questions reflect critical aspects of providing care and are interrelated. What you *can* do establishes the universe of possibilities among which to choose what you *should* do. To the extent your practice skills and resources are limited your ethical options are limited as well. Consequently, there are strong ethical reasons for having excellent clinical and professional skills and being a responsible steward of available resources.

*a. Development of Competence with Compassion™: Ethical Decision-Making in the Changing Culture of Long Term Care*

CARIE initially developed and presented ethics education programs for long term care providers across Pennsylvania. As originally designed the program introduced participants to the four principles developed by Beauchamp and Childress (see page 28) as a basis for ethics in the medical care context and encouraged them to use this approach to resolve ethical dilemmas presented as case studies and vignettes. It became apparent, however, that the “principlist” framework did not adequately address the kinds of ethical dilemmas encountered in the context of long term care. It was clear that what was needed was both a new ethical paradigm that captured the special ethical nature and challenges of long term care and a process for making ethical decisions regarding care issues as they arise in the long term care setting. The lack of existing comprehensive ethics education programs for long term care providers and the inadequacy of the prevailing biomedical ethics model were behind CARIE’s efforts to develop a curriculum focused exclusively on the substance and process of ethical decision-making in long term care.

*b. Care in the long term care setting*

Most thinking about clinical biomedical ethics has taken place within the context of acute care medicine. The nature and concerns of long term care are, however, profoundly different from those of acute care. For example, while acute care focuses primarily on discrete physical problems, long term care involves the “global” well-being of the care recipient, including emotional, spiritual, psychological and social well-being, in addition to physical health.

Moreover, in acute care the exclusivity of the doctor-patient relationship is historically sacrosanct. In long term care, the client or care resident is understood to exist within a web of valued relationships with family members, friends and staff, relationships that may be supported and strengthened by encouraging inclusion in rather than exclusion from care.

Third, acute care encounters between physicians and patients are, for the most part, episodic. Depending upon a person's healthcare needs one might see a particular doctor regularly for a period of time, not see a particular physician for months or even years, or may have only a single consultation. Long term care, on the other hand, is continual and ongoing.

Fourth, within the prevailing medical ethics paradigm the relationship between doctor and patient is conceptualized as one between independent and autonomous agents. The reality of long term care is quite different. Care recipients most often have physical dependencies and/or suffer from dementing illness. In facility-based care the experience of dependency is magnified by the sheer variety of ways in which the quality of the resident's daily life is reliant upon facility staff.

Finally, in acute care, at least traditionally, the interests of individual patients do not compete with each other; rather, the physician’s ethical obligation to each patient is discrete. In long term care, on the other hand, residents’ and clients’ needs may be and regularly are in tension with one another.

Considering the fundamental differences between the experience and goals of acute care and those of long term care it is not surprising that the prevailing bioethical model, developed to reflect the values and obligations within acute care, is not adequate or appropriate to address the ethical issues confronting staff working in long term care. (See Figure 1, below).

**Fig.1 Acute Care vs. Long Term Care**

<b><u>Acute Care</u></b>	<b><u>Long Term Care</u></b>
<b>Medical</b>	<b>Global</b>
<b>Exclusive</b>	<b>Inclusive</b>
<b>Episodic</b>	<b>Continual, on going</b>
<b>Equal/independent parties</b>	<b>Physical/cognitive dependencies</b>
<b>Interests/rights of patients do not conflict</b>	<b>Interests/rights of consumers may conflict</b>

CARIE’s training program is premised upon the belief that an ethical framework that accurately reflects and adequately responds to the reality and scope of the ethical issues entailed in the provision of long term care could only be achieved by listening to long term care providers’ accounts of their actual responsibilities to care recipients. We began asking the early participants in CARIE's long term care ethics education program to identify what they understood their duties to care recipients to be. More specifically, we asked the following question: "When a long term care facility opens its doors and, in effect, invites someone to come live there, what responsibilities have the facility and its staff

assumed with respect to that person?"<sup>18</sup> Not surprisingly, the providers came forward with literally scores of such responsibilities. Long term care givers' descriptive accounts of their responsibilities were integrated with CARIE's concerns and experience as an elder advocacy agency and discussions of the normative values in long term care contained in the literature. The result is *Competence with Compassion™: Ethical Decision-Making in the Changing Culture of Long Term Care*, an ethics education curriculum that proposes *commitment to the care receiver* as the ethical basis of long term care across the entire continuum of care.

*c. The Five Commitments of Long Term Care*

As we studied the array of responsibilities identified by long term care providers, we noticed that they fell naturally within five overarching themes: health, safety, pain and suffering, respect for individuality, and life story. We then framed each of these themes as a commitment that the long term care provider makes to care recipients. These commitments are: (1) To preserve and promote their health; (2) To protect their safety; (3) To ease their pain and suffering; (4) To respect their individuality; and (5) To provide opportunity and support for the continuation and completion of their individual life stories.

Long term care is an inherently ethical undertaking because it is premised upon the fulfillment of responsibilities to vulnerable care recipients. An ethical long term care decision is one that honors the commitments that reflect these responsibilities. The most ethical decision is one that honors the five commitments most fully, whether the subject

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<sup>18</sup> Initial funding for CARIE's long term care ethics project came from the Pennsylvania County Commissioners Association through the Pennsylvania Association of County-Affiliated Homes. The original focus of the ethics education project therefore was nursing homes. CARIE has since expanded the scope of its ethics education program to reach the array of settings in which long term care is provided.

matter is life-sustaining treatment or bathing. Thus, these commitments both describe the ethical nature of long term care and provide a framework for making ethical care decisions.

To identify the above as the five commitments of long term care is not to say that they necessarily define the entire universe of ethical obligations in the provision of care. Long term care staff bring the whole of their humanity and experience into their relationships with care recipients. The five commitments of long term care are not in lieu of the ethical obligations we have to one another as fellow human beings. They articulate the special obligations that we assume when we choose to take on the special task of providing long term care for another.

Of the five commitments comprising the ethical framework for long term care, the commitments to preserve and promote the care recipient's health, to protect safety, and to ease pain are clinical in nature. Fulfilling these commitments requires clinical training, skill and judgment, and attention to best practice models. To honor these commitments long term care staff must have available the human and material resources necessary to meet the client's or resident's clinical needs.

*i. Promote and preserve health*

There are a multitude of avenues for obtaining education and training on clinical issues and it is not a purpose of CARIE's program to provide such training. Yet there are important ethical dimensions within these issues that are specific to long term care settings. For example, within the context of long term care, "the preservation and promotion of health" has a different emphasis and a different goal than it might in the world of acute care. By and large, those receiving long term care suffer with chronic and/or progressive illnesses such as diabetes, arthritis, Parkinson's Disease, cancer, congestive heart failure,

chronic obstructive pulmonary disease, disability and/or dementia. "Health" in these circumstances relates more to the maximization of functional ability than to resolving the underlying condition or disease. In honoring a commitment to preserve and promote the health of care receivers, therefore, we may be focusing our efforts on the ways in which disease and its various treatment options affect their ability to participate actively in their lives, whether in the community or in a nursing facility, rather than on cure.

ii. *Protect safety*

Whereas the preservation and promotion of health is concerned with addressing bodily processes, the commitment to protect the care recipient's safety addresses his or her interaction with the external environment. How can the environment of the long term care setting, whether it is the care recipient's home or an assisted living or skilled nursing facility, be created and/or arranged to provide a physically, emotionally and psychologically safe place for the care recipient to live?

The commitment to protect a care recipient's safety is often experienced as being in tension with one or more of the other four commitments. Honoring the commitment to enhance functioning (for example, mobility) may increase the risk of injury compared with encouraging the person to stay seated as much as possible. Similarly, protecting a resident's or client's safety may seem to conflict with practicing care and respect for her or his individuality or life story. Even adequate pain management may be viewed as incompatible with a concern for the safety of the care receiver. The dilemma posed by a tension between ethical commitments is irreconcilable only if such dilemmas are viewed as requiring yes-or-no, this-or-that solutions. In fact, the dilemmas that arise in long term care rarely require, or are even susceptible to, such either/or solutions. This will be explored

more fully in the discussion below of the *IDEAS for Ethical Decision-Making in Long Term Care* decisional model.

*iii. Ease pain and suffering*

The third commitment a long term care practitioner makes to the persons he or she provides care to is to ease their pain and suffering. Although "pain" and "suffering" are often referred to as if they were a single experience, they are in fact distinct and separable. While pain is a physical symptom, suffering is emotional and spiritual in nature. Thus, one may have great pain and yet not suffer, or one may have no pain at all and yet suffer deeply. The almost universal response to pain is to seek its reduction or, if possible, elimination, but those who suffer may seek to find meaning within the experience of suffering itself. Honoring a commitment to treat and reduce both a care recipient's pain and suffering requires that we be alert to the differences between the two, that we identify the most appropriate person to provide care (e.g., physician, nurse, chaplain, social worker, psychiatrist, psychologist), and that we acknowledge the need for effective intervention in response to these subjective feeling states as much as to more observable or measurable symptoms.

The last two commitments involving concepts of "individuality" and "life story" may be less familiar to long term care practitioners. We will explore these commitments in greater depth in order to clarify their meaning within the *Competence with Compassion*<sup>TM</sup> ethical framework.

*iv. Respect individuality*

*“If I am not for myself, who will be? If I am only for myself, what am I?”*

-- Hillel <sup>19</sup>

This is the commitment that is at the heart of resident-centered or consumer-based care. It is a commitment to respect the particular person in front of us. It may seem that most of the ethical dilemmas encountered in caring for residents or clients in some way involve questions about fulfilling this fourth commitment. One of the reasons that the commitment to show respect for individuality is so challenging for professional caregivers is that its fulfillment often seems to be in tension with other commitments. Sometimes the problem is how to fulfill this commitment and still preserve or promote a resident’s or client’s health or protect his/her safety. Sometimes the issue is that a care recipient no longer has the capacity to make a particular choice for him- or herself or can’t communicate meaningfully with us. Sometimes we are caught between what we know that a resident or client wants or would want and what family members are insisting upon. We may feel that respecting the decisions of our clients and residents discourages us from even discussing those choices with them, let alone trying to influence their choices.

Respect for individuality is related to the more familiar principle of respect for autonomy but the commitment to respect individuality is broader than that. It is broader because respect for individuality requires us to be attentive to more than just the decisions made by care recipients, which is often the focus of the requirement to respect autonomy. Making one’s own decisions is certainly a part of what it means to be an individual but

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<sup>19</sup> From, *Sayings of the Fathers*, a collection of ethical maxims that is approximately two thousand years old. Hillel’s questions reflect the perennial tension between our existence as individual “selves” and our need to be in caring relation with others.

there is much more. As human beings, we exist within a web of relationships that are critical to defining who we are. Thus, our individuality is expressed in a number of ways: Through autonomous decision-making, certainly, but also through our preferences, our enacted values and personal goals, our emotions and creativity and also through our social interactions, personal relationships and community membership.

In meeting our commitment to respect the individuality of each care recipient, it is important to distinguish autonomous decisions from other sort of choices that residents or clients may make. *Autonomous decision-making* refers to a process of making decisions based upon (1) an understanding of the situation and relevant facts; (2) an awareness of alternative choices for action; (3) a weighing of the benefits and risks of each alternative in accordance with (4) a set of values or goals and (5) the communication of a decision consistent with such values or goals. Within Western (particularly Anglo-American) societies, such decisions are accorded great respect and deference because they reflect *self-determination, liberty, and reason*, each a deeply held and abiding cultural value. They are understood to reflect one's most true self. The ability to make decisions in this way is what is meant by decisional capacity. In our culture, we believe that we have a right to be left alone to make such decisions without interference, at least insofar as our decisions don't hurt anyone else.

When a client or resident has the capacity necessary for autonomous decision-making with regard to a particular decision, respecting autonomous decision-making means deferring to the decision made whenever possible. But respecting the process of autonomous decision-making also requires providing and explaining the necessary and relevant information to enable the care recipient to make the best decision. Even in

individuals with some degree of cognitive impairment, autonomous decision-making can sometimes be supported by listening to help identify the problem, simplifying options, exploring possible choices, selecting a particular time of day for discussing the matter, and choosing language that will be more easily understood.

However, many, but by no means all, of the people who require long term care have lost the capacity to think this way. They may not be able to understand the relevant information. They may no longer be able to formulate goals for themselves. They may not be able to state a coherent set of values that they can use to sort through options. They may be unable to understand the potential consequences of their choices, for themselves or for others. In other words, some residents or clients no longer have the capacity to make autonomous decisions. Even so, they certainly may have *preferences* for what they want or wish to do and may express these preferences very clearly in words or in actions.<sup>20</sup>

Care recipients' preferences are an expression of their individuality and should be respected as such. But preferences (as we are using the term) do not warrant the highest degree of deference accorded to autonomous decisions because they do not involve the reflection and thought associated with individualism, self-determination and rationalism, values so highly prized in our society.<sup>21</sup>

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<sup>20</sup> It is important to note that not every choice by a decisionally-capacitated person is autonomous. Individuals who are capable of making autonomous decisions also may express preferences, or choices that are not the result of personal reflection on goals, values, alternatives and consequences but which, as in the case of those who have lost the ability to make autonomous decisions, reflect personal feelings, emotional responses, or what they find pleasing.

<sup>21</sup> Here are two scenarios illustrating the distinction we are making between an autonomous decision and a preference. Case #1: A Jewish or Moslem resident in a nursing home refuses to eat the ham served for dinner because to do so would violate religious rules as understood and practiced by her. She insists on being provided with an alternative meal. This is an autonomous decision as we are using the term because it is made with understanding in accordance with a set of personal values and holds important personal, emotional and/or spiritual meaning for the individual. We would, therefore, defer to it and provide another dinner

So, how should we respond to autonomous decisions and preferences? First we need to ask whether a care recipient is capable of making a particular decision autonomously. If so, we honor such a decision whenever it is possible to do so without harming others because we assume they more deeply reflect the decision-maker's core beliefs, values, or goals. If the choice is a *preference*, we also understand it as a reflection of individuality that calls for respect but we have more leeway in weighing one person's preferences against those of other care receivers and against the competing commitments and needs of care providers as well.

Respecting individuality when a care recipient lacks the capacity to formulate and express even a preference may include making care choices on behalf of the care receiver that are consistent with his or her prior written and spoken directives, consulting with surrogate decision-makers chosen by the care recipient, and being aware of the care recipient's life story as a reflection of values and prior choices. The value of the care

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choice. Case #2: A resident says he wants a prime rib steak rather than hamburger for dinner. Although this is a knowing and intentional statement of choice, it is not an *autonomous decision* as we are using the term in this program and consequently not the sort of expression to which we are required to give the highest degree of deference. The wish for a prime rib steak rather than hamburger (in any case we can think of) is not reflection of the sorts of deep personal values that inform important life decisions but is simply a preference for one meal over another. The mental status of the care receiver is not relevant here. Regardless of whether the resident is cognitively intact or impaired, we would make an effort to respect his individuality by accommodating his preference to the extent possible or would try to work out a compromise. We would not, however, have the same obligation to defer to the choice as we would in the first case. In applying these concepts (autonomous decision and preference) we may use the above examples as establishing paradigmatic cases. To determine whether a particular choice we're dealing with is an autonomous decision or preference (as we're using the terms) we would ask ourselves whether it more closely resembles the first example (a deep religious commitment) or the second (a partiality for one way of preparing and serving beef over the other). If our situation is more similar in relevant ways to the first example, we would defer when doing so doesn't harm anyone else. If it has more in common with the second, we would try to respect the wish, all things being equal, but would not be bound in the same way to defer to it. Determining which example is more applicable may itself call for valuable discussion that may clarify concerns and lead to new insights.

receiver's story as a guide for future decision-making should motivate us to know the client or resident as well as possible while we can so that non-verbal or inarticulate cues about choices may be better understood.

Our daily experience makes us keenly aware that a whole person is comprised of more than cognitive skills. We are also emotional and creative beings. In addition, many, if not most, people believe that human beings have a spiritual dimension as well. Thus, honoring a commitment to respect the individuality of the care recipient also requires being sensitive to and empathically responding to her or his feelings. It calls for providing opportunities for creative expression and experience and giving recognition to such efforts. It means honoring and attending to the care recipient's religious beliefs and spiritual needs. Respecting the individuality of the care recipient also means keeping their confidences and respecting their privacy.

Despite the cultural and historical importance accorded to individualism, we know that our emotional and psychological (and even physical) health is very dependent upon our relationships with others. Thus the relational aspect of the individuality of each person requires that we afford opportunities for social interactions, that we respect and protect the particular relationships that the resident or client brings into long term care as well as those formed through the experience of receiving long term care, including relationships with caregivers and others, and that we facilitate and support care recipients in the creation of community.

- v. *Provide support for the continuation and completion of the care recipient's life story*

*"I was not the self I knew myself to be."*

Sekou Sundiata <sup>22</sup>

We are all aware of the dread with which most people anticipate needing long term care. Part of the reason no doubt lies in a belief by many that the dependency that triggers the need for long term care and the loss of control over their life and environment, either through the need for "intrusive" home care providers or through a move to a nursing home, represents the end of one's particular life story even while one's body continues to live. Paraphrasing one bioethicist, biographical life has ended while biological life goes on.<sup>23</sup> But surely this need not be the case. The need for long term care can be, *should* be, a next chapter in a unique and on-going life story. In order to understand and care for a particular individual, we must know the life that we are now entering as caregivers and necessarily becoming a part of. We must ask "Who is this person?" and we must listen for the answer.

Too often most of the information we have about a long term care receiver comes from sources other than the care recipient her- or himself. Medical records, admissions forms, and information from family members often are the bases for our knowledge of the "history", which we accept as the account of who that person has been and is now. But each of these narrative sources speaks in a voice that is its own, reflecting its own viewpoint, its own concerns, even its own biases. To care well for the person in front of us

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<sup>22</sup> From an interview with performance poet Sekou Sundiata originally broadcast on *Fresh Air* on National Public Radio on November 20, 2002, rebroadcast on March 25, 2005. Last downloaded on October 6, 2007 at <http://www.npr.org/templates/story/story.php?ld=4561097>.

<sup>23</sup> J.Rachels. 1986. *The End of Life*. NY: Oxford University Press.

requires that we see that person not just through the prism of others' eyes but, much more importantly, through that person's own eyes; that is, as he or she knows him/herself.

The awareness, sharing and acknowledgment of one's life story hold great value for any individual. Many of us spend a great deal of time engaged in giving and receiving parts of our own and others' stories. As explored below, this value is magnified for those who live within the context of long term care. Bringing the resident's or client's own narrative into the long term care setting is critical to the continuation of that life story in the following ways

*a. It helps maintain self-identity*

Our life story is how we know ourselves and how we locate ourselves with respect to the world and the people around us. Imagine, for example, if you were to awaken one morning with total amnesia about everything that had happened to you before you awoke. You have apparently suffered no injury and have the physical ability to go about your life much as you wish. How would you know what to do next? Where would you go? You would be desperate to know "Who am I?" and to find the answers to such questions as "Where do I live?" "Do I have a family?" "Where do I work?". In short, you would be desperate to get your story back in order that you might know *who you are*.

The need for long term care, whether in one's own home or in a nursing facility, often deals a profound blow to an individual's sense of who he or she *is*—literally the person's place in the world changes. The care recipient's relationship to and experience of those people and things that gave life meaning and shape, perhaps for decades, such as home, possessions, routines, and relationships with neighbors and others in the community, disappear or are dramatically altered. Encouraging residents to tell their stories, the stories

that preceded and include the need for long term care, provides an opportunity over time for the creation of coherence out of what may initially feel like a story and an identity that are irreparably ruptured. It permits the re-visioning of the care recipient's story as a single continuing life.

*b. It illuminates meanings*

The events and choices of our lives derive their meaning from the way they fit together with what has gone before. For example, take the statement "John is walking in the park." Suppose John works in your office. You know that John's wife left him ten days ago. He has lost weight, his eyes are red-rimmed, and his clothes are rumpled, he smells of alcohol. It is ten o'clock on a Tuesday morning and there are three businessmen who had a nine-thirty appointment with him sitting in his office but John is not there. When you ask his assistant where John is she answers, "John is walking in the park." In the context of this story we give a particular meaning to the fact that John is walking in the park. Now suppose that you are told instead that eighteen months ago John was in a terrible car accident. He was in a coma for four days. After five weeks in the hospital he was moved to a rehabilitation facility where he lived for eight months. It's ten o'clock on a Tuesday morning. You call him at home and his wife says, "John is walking in the park." The identical fact takes on a completely different meaning when we are aware of the story of which it is a part.

In order to know what something as seemingly simple as a walk in the park means *to John*, we need to know John's story. In the same way, we need to know a care recipient's story in order to know what the meaning of a particular decision is for him or her. What will it mean for Mr. Logan, a former football player, to use a wheelchair? What

does it mean to Mrs. O'Malley, who used to cook for her large family, to be fed? What meaning does the decision to forego life-sustaining treatment hold for Mr. Geffin? What does it mean to Mrs. Jefferson to be bathed by nurse aides? The significance of any of these decisions for the care recipient can only be understood if we know the story of which it is becoming the newest chapter.

*c. It individualizes the care recipient*

Charts, case files and protocols are absolutely essential for identifying critical data, for organizing them in an efficient and useful way and for responding with efficiency and consistency to care issues. They permit standardization of practice. "Charting" calls for communicating information about a resident or client in a particular voice, one that is professional and objective. Protocols are a way of recognizing what situations or cases have in common and responding in established effective ways. Both are an integral part of providing good and efficient care, especially when time is the resource most at a premium.

In the face of incentives to create commonalities, it is the particular facts of a resident's or client's life that keep that person's individuality foremost and make that person's "case" unique. It is what enables us to recognize how Mrs. Lopez's wandering may be different from Mrs. Lyons', how Mr. Caruso's depression is different from Mrs. Hartley's. Learning the care recipient's story is a counterbalance to the tendency to see only what we have seen before and therefore expect to see again, our tendency to recognize the general similarities among those we care for but to miss the specific differences.

*d. It provides a guide for decision-making*

In situations where a care receiver lacks the capacity to make care decisions and decisions must be made by surrogates or, in some cases, care providers, knowledge of his

or her story can be of great help in making a decision that gives coherence to that story and that carries the story forward in a way that makes sense. Care recipients have developed a powerful storehouse of wisdom in their own life stories. Each care recipient is the world expert on his or her own story. It contains many examples of what has worked for this particular person when she or he has had a problem in the past and thus what might work now. Each of us who provides care needs to begin to learn something of the power of that story.<sup>24</sup>

Knowing the care recipient's life story gives us a window through which we may discern the values, people and things that were important to that person. Knowledge of past choices about how to live can guide those who now must decide in the person's stead. It permits decision-making that is consistent with the individual's previously lived values, with his or her "ways". It expands our ability to take the other's perspective, to discern the choice that person would have made himself were he able.

*e. It helps to create social connection*

The value of learning a care receiver's life story lies not only in the information that is imparted but also in the relational act of communicating and receiving the story itself. Listening as someone tells his or her story, not just at one sitting but over time, creates connection. The experience of being listened to as one recounts one's own story, of being heard, can be one of deep sharing. This story telling may call forth reactions and responses from the listener, who may then share parts of her or his own life. The

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<sup>24</sup> P. J. Barker and P. Buchanan-Barker, 2005. *The Tidal Model: A Guide for Mental Health Professionals*. New York: Brunner-Routledge.

formation of relationship in this way offers an antidote to the isolation that often accompanies the experience of needing and receiving long term care.

*f. It helps to sustain memory*

The process of reminiscing can be an aid to memory. Accurate prompts, observations, questions, and comments from the listener may reinforce care recipients' recollections of their experiences and evoke additional memories. Through this process, the care recipient's current memory may be strengthened and her sense of the narrative coherence of her life increased.

*g. It encourages feelings of empathy, compassion, and understanding*

In hearing a resident's or client's life story, the challenges overcome, the ways in which the person cared for others, the ambitions that went unrealized, the events that gave pleasure, the times that brought sadness, our own emotions are engaged. We may be able to identify having feelings similar to that person's and may have confronted some of the same challenges. Our differences may diminish and the ways we are alike become apparent. We gain understanding, empathy, and compassion.

**4. "Ought implies can"**

Too common in long term care is the situation of the "unbefriended" person suffering with dementia. These individuals lack both the capacity to make decisions for themselves and a relative or friend who knows them well enough to make decisions that reflect what their own choices would have been. How do long term care providers honor their commitments under such circumstances?

"Ought implies can" is a well-recognized maxim of ethics. It means that saying we should (ought to) do something presumes that it is actually possible for us to do it.

Applying this maxim to the ethical framework we have described, the impossibility of fulfilling a particular commitment may relieve us of the moral obligation to do so. For instance, we cannot provide opportunity and support for the continuation and completion of the care receiver's life story if we have no way of learning the story as she would have wanted it told. It may not be possible to fulfill a commitment to respect an individual's decisions if he lacks decision-making capacity. When faced with a commitment it is impossible to honor, we continue to be bound by our remaining commitments including the preservation and promotion of health, the protection of safety, and the palliation of pain and suffering. It is essential, however, that "impossible" not be used to mean expensive, inconvenient, time-consuming, or problematic.

#### ***IV. IDEAS for Ethical Decision-Making in Long Term Care***

*"Knowing is not enough; we must apply. Willing is not enough; we must do"*

*-- Johann Wolfgang von Goethe*

The five commitments of long term care set forth above describe the ethical responsibilities we commit ourselves to fulfilling when we choose to take on the role as a provider of long term care. They have been derived from the responsibilities that long term care providers identified as those they bear toward care receivers. They therefore reflect the substance of ethical long term care as actually practiced and lived daily by care providers. Every so often, however, a situation arises in which how best to fulfill these commitments is unclear. CARIE has developed a five-step process called *IDEAS for Ethical Decision-Making in Long Term Care (IDEAS)* for working through such a care dilemma to reach an ethical solution. *IDEAS* constitutes a companion piece to the ethical framework described above.

Each letter in the word IDEAS stands for a step in the decision-making process. These steps are: (1) **I**dentify the ethical dilemma and gather information; (2) **D**evelop a care recipient narrative; (3) **E**xplore all conceivable options; (4) **A**ssess the options; and (5) **S**et a course of action and create an implementation plan.

### **Step 1: Identify the ethical dilemma and gather information**

- *Identify the ethical dilemma*

We face an ethical dilemma when we have a conflict among our commitments to the care recipient. Working through the *IDEAS* process will help us resolve the dilemma.

The *IDEAS* process for guiding ethical decision-making is based on the previously discussed commitments that long term care providers have to care recipients: (1) To preserve and promote their health; (2) To protect their safety; (3) To ease their suffering and pain; (4) To respect their individuality; and (5) To provide opportunity and support for their continuing life story. An *ethical dilemma* arises when there is a tension between two or more of these commitments. Identifying the ethical dilemma, then, involves recognizing which two or more commitments to a care recipient conflict in a particular situation.

In defining the ethical dilemma in this step, it is important to keep in mind that the dilemma *belongs to the care provider*. It does not lie in the behavior of a care receiver or his family or other staff (e.g., Mrs. Hall refuses to take a bath). Nor do the medical or other facts of the situation define the dilemma (e.g., Mr. Andrews' breathing is becoming labored; Mrs. Bloom has begun choking when she takes food by mouth). These situations raise care issues, present clinical problems. The ethical dilemma, however, is the conflict experienced *by the caregiver* when two or more of her or his commitments to the care

recipient are in tension. Identifying the ethical dilemma, then, requires identifying which commitments are in tension.

- *Gather information*

Information gathering involves bringing together the relevant facts about this ethical dilemma. It includes *identifying stakeholders; gathering available data and identifying needed missing data*. Stakeholders are any persons who are concerned with and/or affected by the ultimate resolution of the issue being addressed. In addition to the care recipient, stakeholders may include the family, staff who are concerned with and/or affected by the resolution, other residents/clients, administration, board/institution, regulators, insurance providers, law enforcement, and the broader community. Available data may include medical data (diagnosis, medical history, medical status, prognosis); psychosocial history, cognitive status, speech/physical/occupational therapy reports, dietary reports, the existence of an advance directive, values/preference scales, pain scale, and anecdotal information from staff and/or family. Although this step may take a good bit of time, it is critically important because we need to be sure to thoroughly describe the situation and be clear about the dilemma we are trying to resolve. This step requires us to “spell out the facts” and provides the foundation for moving toward possible solutions.

It is important to recognize that we may not always have all of the information that we would like available to us to assist in resolving a dilemma; however, gaps in information should be acknowledged and an effort made to discover the needed information if time permits. Once we have gathered all of the pertinent information reasonable available to us, we can then move on to thinking more specifically about the care recipient involved to add depth to our understanding of the situation.

## **Step 2. Develop the care receiver's story**

Developing the story, or narrative, of the care recipient shows how long term care affects real people. Charts containing clinical diagnoses and treatment plans love data and statistics but stories fill in the conflicts, the emotions, the values, the joys and pains of being somewhere on one of those charts. In stories, we see the faces that long term care is all about. This step incorporates the commitment to provide opportunity and support for the care recipient's continuing life story into the decision-making process.

Histories and charts contain many facts, but to really know the person we need to know how these facts affect her or him. We need to create a narrative and in order to create a true narrative; we need to listen, with our ears but also with our heart, to the person at its center. We want to know, for example, what is the care receiver's understanding of the situation? How does she or he understand what's happening and why it's happening? In considering this particular person's story, we're thinking not only of his or her life before the need for long term care arose, but since as well. Has this situation arisen before? How has it been handled? What has worked in the past to resolve the dilemma we're facing now with this individual?

Our personal stories are ours to tell, but not exclusively ours to tell. Those who know us also can contribute to the telling. Of course, the closer the relationship, the more central the voice. So, caregivers too may have a contribution to make to the telling of a care recipient's story. But it is important to remember that others may contribute to but not replace the story at the core.

### **Step 3. Explore all conceivable options**

We now have the background information we need to begin our ethical decision-making. Any care decision requires that we ask what we can do, what we must (must not) do and what we should do. So first, we need to establish what we *can* do. This step is all about brainstorming as many options as we can for addressing the problem we've identified: We are not yet thinking about the other two care issue questions, "*What must we do?*" and "*What should we do?*" We will address those next. Our task right now is to think as creatively as we can and to generate as many different ways of responding to the problem as possible. Even options that we know will be eliminated in the end because it's obvious to us that we must not or should not do them may be helpful at this stage because they may stimulate us to think of other options that would not otherwise have occurred to us. Once we have identified all the possible responses to the problem, we will choose the most effective way to resolve the ethical dilemma. In the next step we will assess the options to determine how we *should* resolve the tension among our commitments to our client or resident.

### **Step 4. Assess the options**

The *IDEAS* process encourages the consideration of the full array of possible responses to an issue, from which a comprehensive course of action may be derived. In Step 4 we evaluate the options we have generated in terms of the remaining two questions: What must we (not) do? What should we do? The first thing that we will want to do is to go over the possibilities and see if there is anything among them that we must not do. In other words, is there anything among the proposed options that relevant laws or regulations

prohibit? If so, we take that option off the table because it really can't be included in any solution to the dilemma that we might create.<sup>25</sup>

We now turn to the information we have gathered and the remaining options we have thought of. We have two tools we can use to evaluate these options. The first is our awareness of our commitments as long term care providers to the care receiver's health and safety, to alleviating her suffering and pain, to respecting her individuality as expressed in her decisions, choices, values and preferences, and to maintaining and continuing the integrity of her life story as much as possible. Our second tool is our understanding of our dilemma – that is, how the situation we face creates a conflict among those commitments.

So, armed with these tools, we survey the options. An important question that will affect our evaluation of our options is whether the care recipient has the capacity to make an autonomous decision. That is, does he have the ability understand the alternatives, reflect on his personal values and goals and thoughtfully consider the consequences of choosing one or another option? If this is the case, we will whenever possible defer to that decision. Sometimes we may not be sure whether a care recipient has the ability to make a decision that is autonomous in this way and we may need the expertise of a psychiatrist or psychologist to help us determine that. Sometimes, however, our day-to-day knowledge of the person and the circumstances of the decision he or she is making are enough to let us know whether it is autonomous.

If we determine that the person lacks the capacity to make such a decision autonomously we might not take the same deferential stance toward the decision-making as

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<sup>25</sup> There may be situations in which it is determined that doing what is ethically right requires violating a law or regulation. Such decisions are so situationally and organizationally specific that while we acknowledge them here we do not address them in this program.

we would if he or she possessed such capacity. However, our commitment to a care recipient's individuality includes respecting his preferences as well as his autonomous decisions. So we will think about how we can respect the care recipient's preferences while still keeping our other commitments to him and to other care recipients and responding to concerns of family, staff, administrators and the long term care organization itself.

It is important to remember that concluding that a decision in one situation is not an autonomous one does not mean that a person lacks the capacity to make any autonomous decisions. Except in extreme circumstances (e.g., persistent unconsciousness, coma, profound dementia or mental retardation) we arrive at that conclusion about a specific decision only in the context of particular facts and remain open to the possibility that tomorrow morning or even 15 minutes from now the person may be very capable of making an autonomous decision about this or another issue.

Rarely does the best solution to a care dilemma in long term care consist of a single word (e.g., "yes" or "no") or action. So, keeping in mind our commitments as long term care providers, we consider how to put the "can do" options together into one or more alternative action plans that allow us to do what we "should" do, that is, fulfill our commitments as fully as possible. .

### **Step 5. Set a course of action**

This is the step in the process where we need to get specific and decide exactly what we will do, when we will do it and who the plan involves. Each of the one or more possible courses of action that emerge from the previous step offers an alternative for resolving the dilemma in a way that fulfills our ethical commitments. Is there one that clearly seems the best way under these particular circumstances? Here we might consider

fairness to other care receivers, other demands on our time, available resources, and so forth. Does it make sense to start with one, see if it works and then, if necessary try a second?

Although our ethical decision-making has been focused on our commitments to the care recipient, no solution to our ethical dilemma will be complete if we do not consider the impact of that decision on others who will be affected by it. Although the *IDEAS* process is resident- or client-centered in that it focuses on our commitments to the care recipient, any concerns of the stakeholders identified earlier (in the “I” step) need to be addressed in some way in order for the resolution of the dilemma to be complete. There may, of course, be stakeholders who disagree with all or part of the action plan that has been developed. In that case, we might want to consider whether the challenge raises issues we had not thought of. Possibilities for responding to disagreement include explanation, education, counseling, and mediation.

Sometimes just explaining to a family or staff member how a decision was reached will change their own thinking about the issue. One of the ways in which the *IDEAS* process can be valuable is in describing to others the way a decision was arrived at and the factors that were taken into account in reaching a particular conclusion.

At other times it may be appropriate to provide education on relevant issues. For example, a family member may not understand the risks or burdens involved in performing a particular procedure. Television hospital shows have led many people to believe that CPR is almost always successful and that tube feeding is completely benign, without any downside regardless of the frailty of the person receiving it. Most people are unaware of the risks that physical restraints pose. It is important that *everyone* who is involved in

caring about and caring for a resident or client have a realistic understanding of the actual benefits and burdens of options. In other words, that they have an accurate idea of what can be done as they reach their own conclusions about what should be done.

Insistence upon or resistance to particular care decisions may be reactions to grief or even to old family tensions and dynamics, for example sibling rivalries over who is in charge or feelings of guilt or anger over past wrongs. In these situations, counseling by a social worker or psychologist may permit family members to look past their own concerns at least for the moment and to focus on what's in the best interest of the care recipient.

Finally, it may be helpful, particularly if disagreement over care options is between the family and the care provider, to bring in a neutral party to mediate the dispute. Often a third party, because he or she is seen as impartial, will have the trust of all concerned and will be able to help everyone reach a consensus that they could not reach on their own.

#### **V. Record keeping and following up**

It is important to keep a (HIPPA-complying) record of the factual situation, the dilemma and how it was resolved. Likewise, it will be helpful for addressing similar issues in the future to follow-up, to pay attention to what happened and how well the chosen course of action worked. Were those involved satisfied with the outcome? How might we improve the outcome next time? This record will become part of the “institutional memory” of our organization and a resource for future use.

## VI. Conclusion

“Human beings long for connection, and our sense of usefulness derives from the feeling of connectedness. When we are connected – to our own purpose, to the community around us, and to our spiritual wisdom – we are able to live and act with authentic effectiveness.”

-- Malidoma Patrice Some<sup>25</sup>

This paper has set out a new framework for understanding the ethical underpinnings of long term care and a methodology for addressing ethical dilemmas arising in the course of providing care. It's important to keep in mind that the goal in using the *IDEAS* process is not to make a “perfect” decision, but to make the best, *most ethical*, decision we can under the circumstances. *IDEAS* is a tool that helps us to take a step back from the problem and remind ourselves to view the situation fully and to pay attention to the context in which this dilemma has arisen.

We began by recognizing that the ability to think and act ethically is an essentially human gift. In choosing to act ethically, in honoring our responsibilities to each other, we become connected not only to each other but, as Malidoma Some writes, to our own purpose and our own effectiveness. It is our hope that in suggesting a way of thinking about the ethics of long term care that is grounded in the commitments we make to those whom we care for we have contributed to the possibility for connection, purpose and effectiveness of both the providers and the receivers of care.

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<sup>25</sup> M.P.Some.1998. The Healing Wisdom of Africa. New York: Tarcher.