

Understanding Decision-making Capacity: A Jewish Consideration of Ethical Issues Surrounding Care Decisions for Elderly People with Dementia

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Framing the Question

This essay begins within my own family. I have an elderly aunt who sits at home all day. Even though she is unable to properly care for herself, she adamantly refuses to move to a nursing home or even to accept in-home nursing care. In her current situation, she is at a high risk for falling, endangering herself by misusing her appliances, and failing to consistently take her medicines. On the other hand, most conversations with her flow quite normally and she can communicate very clearly her reasons for wanting to remain at home without help. I certainly wish that she would make a different decision, but, after talking with her, I am not convinced that her capacity to make that decision is so thoroughly impaired as to permit others to override it.

My aunt's situation raises many important ethical questions for my family and for all those with an interest in her welfare: Is she competent to make medical and other important decisions for herself? How do we decide? If she is not competent, who should have the final responsibility for decisions about her care? To what values should that person or group of people give priority in making treatment decisions? What weight should be accorded to her expressed preferences? Are there some areas in which we should accept her decisions, but others in which we should not?

In this essay, I hope to open a discussion about the ethical issues involved in decisions surrounding treatment and care for elderly people with dementia. I will present some of the arguments current among medical ethicists together with the teachings of classical Jewish tradition in an effort to explore how each field might enlighten, enhance, or critique the other. I hope that this conversation will help caregivers, clergy, and medical professionals to better articulate and evaluate their own priorities, so that, as decisions need to be made, the people involved will share a full awareness of how to best help and honor someone with dementia.

Dementia affects over 10% of all Americans above the age of 65. Its symptoms can include a significant progressive loss of mental acuity, impaired judgment, reduced decision-making capacity, increased difficulty communicating, and changes in personality, mood, or behavior. As memory loss severs a person's connection to others, to what is safe, and to what is familiar, dementia is often accompanied by severe depression. This depression can have the cyclical effect of further alienating the person from others and drawing the person even more deeply into an internal world that those on the outside cannot access.

Dementia is often stigmatized in our society. Engaging a person with dementia rightly raises our most profound fears of fragility, loss of self, and death. It is a perfectly human response to seek to avoid the situation and deny the reality of the pain it causes. Without understanding and resisting that instinctive response, many are tempted to protect themselves from the pain and fear of the situation by depersonalizing the one with dementia. This can take the form of deceiving the person in order to force compliance; not giving the person control over his or her own choices; infantilizing the person through tone of voice or terms of endearment; and objectifying the person by not making an effort to listen to his or her concerns. In our consideration of when to accept the treatment decision of a person with dementia and when to override that decision, we must keep the above concerns in mind in order to avoid engaging in a process that depersonalizes the person with dementia even further.

While there is a wide range of opinions presented in medical and ethical literature regarding how to define and measure legal competence or decision-making capacity, the core debate revolves around the challenge of balancing two competing goods: individual autonomy and beneficence. Individual autonomy is a person's right to

make decisions for him-or herself, even when those decisions conflict with what others would prefer. Autonomy is a cornerstone of Western ethics, made paramount by Kant, and is reflected in the biblical concept of *b'tzelem elohim* – the belief that we are each, regardless of individual differences, made in God's image. In the words of ethicist Howard Brody, autonomy represents “free action which authentically represents an actor's values and beliefs, and which results from effective deliberation and reflection in the absence of controlling influences.”¹ In this context, respecting autonomy requires us to accept as valid a person's decision about his or her treatment, even when it is not the decision that we wish the person would make.

Beneficence is striving towards the health, welfare, and well-being of all. It represents our moral obligation to protect and care for everyone in our society, especially those least able to care for themselves. It demands that we work to prevent people from hurting themselves and others. This obligation is expressed in many forms throughout the Bible and rabbinic literature, maybe most clearly in Leviticus's dictate, “Do not stand idly by the blood of your neighbor.”² The different voices in this discussion all have ideas about how to best manage the balance between autonomy and beneficence. The core question they share in common is: At what point is one's mental process so impaired that respecting that person's autonomy no longer constitutes a benefit worth the risk of that person suffering?

Defining Legal Competence and Decision-Making Capacity

In order to answer this question, we will need to define the elements that make up legal competence and decision-making capacity. While the two terms are often used interchangeably, in this discussion, they will signify different concepts. Competence refers to a strictly legal standard determining whether or not a person's decision is legally binding. The term “competence” denotes a simple binary: one is either competent or not competent to make a decision. Decision-making capacity, on the other hand, refers to a point on a spectrum. That point can fluctuate, often significantly, for the same person at various times, in various states

¹ Brody, H. “Autonomy Revisited; Progress in Medical Ethics” *Journal of the Royal Society of Medicine*, 1985; 78: 380-387.

² Leviticus 19:16.

of health, and with respect to various matters. In assessing decision-making capacity, we are not looking for a line to distinguish between sufficient or deficient capacity; rather, we are looking for the factors that comprise and the behaviors that signify more or less impaired mental capacity. Understanding the fluidity of decision-making capacity, Maimonides is presciently vague when he relates the law which sets the criteria to determine if someone is mentally competent to testify in court:

This matter is decided according to what the judge sees; for it is impossible to set the standard in writing.³

Following Maimonides' lead, we will not endeavor to construct a formal rule by which we can measure one's mental capacity; rather we will look at the different factors which comprise decision-making capacity in an effort to better assess when it is functioning smoothly and when it is impaired. I will add the caveat that, in any situation, decision-making capacity is initially assumed to be unimpaired until strong evidence surfaces suggesting otherwise. Making decisions which are not to the liking of others does not constitute sufficient grounds to question one's capacity to make decisions. Rather, only when evidence is present that one's process of making decisions might be impaired, does the question of understanding and assessing capacity become relevant.

Paul Appelbaum and Thomas Grisso outline four important aspects of decision-making capacity which will serve as the foundation for our discussion.⁴

1) Understanding Relevant Information

We assume that people who cannot understand what they have been told about a treatment option are not competent to decide whether to accept or reject it. The understanding necessary here is not simply a basic comprehension of the words communicated but a deeper understanding of their fundamental meaning. That is, we expect a person to understand the causal relationships, the risk-benefit ratio, and the likelihood of various outcomes possible from each decision. In discussing this point, Ruth Faden and Tom Beauchamp emphasize that it is not only important for the person to understand what he or she is told, but also to understand his or

³ Maimonides, *Mishne Torah, Hilchot Edut* 9:10

⁴ Appelbaum, P. and Grisso, T., "Assessing Patients' Capacities to Consent to Treatment", *New England Journal of Medicine*, 1988; 319:1635-8.

her critical role in the decision-making process.⁵ If a person does not understand that the decision he or she makes will initiate one treatment process while terminating other possibilities, we cannot consider the person's mental capacity functioning free of impairment.

Reduced attention span, memory loss, and impaired cognitive function all present threats to understanding. In assessing understanding, we should ask a person to repeat and paraphrase information that is given. It is the obligation of caregivers to provide that information in terms that the person is likely to understand, taking into account language, background knowledge, and formal education. A person cannot be assessed as having impaired decision-making capacity if that person never had the opportunity to make a valid decision because of missing, faulty, or poorly communicated information. We can assess one's understanding of the role he or she plays in the decision-making process by asking if he or she understands the consent process and why it is necessary.

2) Appreciating One's Circumstances

People can understand something generally without understanding what it means for them specifically. That is, one might be able to explain something he or she has been told without grasping the implications it has for his or her own future. In our context, does the person understand that he or she is ill? Does the person understand the likely consequences of the various options? Is the person able to envision the potential risks?

Delusions and denial can coexist with cognitive dysfunction in such a way that impairs the person's ability to accurately perceive the nature of his or her condition, to evaluate the probable outcomes, and to appreciate the motivations of caregivers. Assessing this aspect of capacity requires that we ask a person how he or she conceives of the illness, what is likely to follow from each possible treatment decision, and why different people involved may be suggesting different options.

3) Manipulating Information Rationally

This involves the ability to assign different values to various bits of information and to employ logical processes in order to compare

⁵ Faden, R. and Beauchamp, T., *A History and Theory of Informed Consent*, Oxford University Press, New York: 1986.

the different options. It is not our job to dictate what values the person should or should not assign to different factors, but we must assess if those values assigned remain consistent through the decision-making processes. Is the person able to evaluate multiple options simultaneously in a way which reflects the weight previously assigned to each bit of relevant information?⁶

Obstacles to the rational manipulation of information include delirium, depression, anxiety, phobia, mania, anger, and apathy. Even people with high levels of decision-making capacity are unlikely to be able to detail all the factors relevant in their decisions, and to present the relative values assigned to each. Rather, in assessing this aspect of capacity, we simply expect a person to be able to defend the choice he or she has made and to identify the major factors behind that choice.

4) Communicate Choices

Western ethicists and legal codes almost universally assume that the ability to communicate one's choice is a necessary component of decision-making capacity. Beyond simple communication, this aspect of capacity entails being able to maintain a consistent choice over time. While it is certainly appropriate for a person to change his or her mind more than once when it comes to major life-changing decisions, repeated reversals of intent may signify a serious cognitive dysfunction.

The inability to communicate consistent choices may coincide with scattered thinking, a disruption in short-term memory, or extreme apathy. We can assess consistent communication capacity by asking the person involved what he or she wants several times, allowing opportunities to reopen the conversation when appropriate. Memory loss alone should not stand as sufficient grounds to assume an inability to maintain a choice consistently over time. The fact that a decision is forgotten from one day to the next may not be relevant, as long as the patient consistently makes

⁶ Interestingly, American courts have generally avoided assessing the ability to manipulate information rationally. See *In re Milton*, 505 N.E.2d 255 (Ohio 1987) and *In re Yetter*, 62 Pa. D. & C. 2d 619 (1973). Instead, they have ruled in several cases that as long as one understands and appreciates the relevant information, he or she has a right to make a decision which outside observers see as irrational.

the same choice when presented with the same options and information.⁷

In addition to the above four aspects of capacity which Appelbaum and Grisso detail, we should add two others often found in the literature of informed consent:

5) Intentionality

The decision should not seem severed from the rest of the person's reality and goals. We expect a person to commit him or herself to clinical care, or its absence, as part of an organized program to realize that person's goals and values. Intentionality, in this sense, means deciding on a plan of care consistent with the person's goals. If the person involved has clearly expressed goals which seem to be inhibited because of the care decision being made, the caregiver should stand alerted to the fact that the person with dementia's decision-making capacity may be impaired in such a way that the person does not recognize the negative impact of his or her decision on the goals he or she holds.⁸

Intentionality may be hindered by mood disorders, extreme anxiety, confused thinking, and a reduced capacity to think abstractly. We can assess it by asking a person what values are important to him or her, and how a particular decision may work towards or against those values. As the treatment, or non-treatment, process continues, if a person is unable to carry out the plan he or she has set, unable to monitor him-or herself for significant changes, or unable to alter the plan as necessary, the person is likely working against the very goals he or she had expressed in adopting the plan of care initially. These possible signs of impairment should be addressed immediately by caregivers in assessing intentionality.

It is easy to dismiss a person's judgment when his or her stated values have changed from where they may have been for much of that person's life, but we are not assessing if a person's values are appropriate, only if the decision-making process allows that person to realize his or her values through the choices being made. We also should remember that, as people face illness and the end of life, it is

⁷ Fellows, L., "Competency and Consent in Dementia", *Journal of the American Geriatrics Society*, 46:922-926, 1988.

⁸ Workman, R., McCullough, L., et al., "Clinical and Ethical Implications of Impaired Executive Control Functions for Patient Autonomy", *Psychiatric Services* 51:359-363, 2000.

quite common for a person's goals to shift. An elderly person with dementia should not be considered incompetent solely because that person has a new and unexpected value structure, inconsistent with values expressed at a time of better health.

6) Voluntariness

Respecting autonomy demands that a person's decisions must be free from external coercion or manipulation. Hallucinations, delusions of thought control, and the automatic obedience of catatonia are some of the most extreme obstacles to voluntary decision-making that often accompany dementia. Other people with dementia will respond non-voluntarily to verbal cues or other prompts from their environment. This stimulus-bound behavior suggests an impaired ability to act and make decisions free of external controls. Some people with dementia experience paranoid delusions, inclining them to decide against whatever a caregiver is suggesting; on the other hand, other people with dementia feel so dependent on their caregivers that they are willing to agree to whatever they believe the physician or family members want.

To maximize the potential for voluntariness, caregivers must ask a person with dementia about his or her decisions in the setting where that person is most comfortable. The person with dementia should be provided the opportunity to discuss his or her decision at different times with different people, so that if he or she feel coerced by one person, the discussion can proceed at another time without that person present. Caregivers should ask: Is this really what you want, or is it what you think I want?

The Debate in Jewish Legal Sources

The questions we are considering force us to examine what weight we give to individual autonomy relative to beneficence. At what point are we comfortable violating someone's right to make autonomous decisions in an effort to secure his or her health and well-being? While the terms used in classical Jewish sources do not overlap exactly with the vocabulary of the debate thus far, Jewish tradition offers us some important guidelines in weighing these competing goods against each other.

Classical Jewish legal sources rarely distinguish between an elderly person with dementia and other situations of impaired mental capacity. Consequently, much of what we will see in our examination of the texts will use the awkward language of *shoteh* –

an insane person – to describe any person with reduced decision-making capacity, including the elderly with dementia. We begin with the discussion of the Talmud, quoting a teaching of previous generations:

Who is a *shoteh*? One who goes out alone at night, one who sleeps in the graveyard, one who tears his clothes.⁹

The Talmud then introduces a debate about how to interpret this earlier text:

Rav Huna said: once all of them are present at once.

Rabbi Yochanan said: [it is sufficient with the presence of] even one of them.

Rav Huna sets a higher threshold than Rabbi Yochanan to be considered mentally incompetent; for Rav Huna, one needs to exhibit all three of the listed behaviors at one time in order to be considered a *shoteh*. Setting a lower threshold, Rabbi Yochanan is willing to consider someone a *shoteh* if he behaves in only one of the three ways listed above. The debates continues and eventually the weight of the Talmud sides with Rabbi Yochanan's lower standard. At this point, a final segment of the opening text is brought and, the Talmud suggests that, if Rav Huna had known this additional piece, he would have reversed his opinion.

| | Restrictive | Middle Ground | Broad |
|------------------|---|--|--|
| Proponent | Rav Huna | Rabbi Yochanan (Supported by Simcha of Speier and Avigdor HaCohen) | Maimonides |
| Criteria | Three specific abnormal behaviors must be present simultaneously. | Any one of four possible abnormal behaviors must be present. | Person must exhibit some confusion or impaired judgment. |

Who is a *shoteh*? One who destroys all that is given to him.

If we follow the interpretation of the original text to which the Talmudic discussion leads us, we find that there are four signs of mental incompetence, all representing abnormal behavior and none

⁹ *Chagiga*, 3b.

directly assessing the person's decision-making processes: going out alone at night, sleeping in a graveyard, tearing one's clothes, and destroying one's possessions.

Post-talmudic commentators debate as to whether these signs are meant to be understood as mere examples, or as very specific indications of mental incompetence. Rabbis Simcha from Speier and Avigdor HaCohen both demand that these specific signs be present before a legal declaration of incompetence can be made.¹⁰ The consequence of their rulings is to narrow the category of the *shoteh* to people exhibiting a very limited set of behaviors.

Maimonides, on the other hand, describes a much more broad set of criteria for legal incompetence. He writes:

Any person who has deficient reasoning or who find that his thinking is frequently confused about one matter among many matters, even though he may speak and ask questions appropriately about other matters, he is invalid [to testify in court] and is considered to be a *shoteh*.¹¹

According to this definition, legal incompetence does not center around abnormal behaviors but is determined solely by the acuity of the person's mental processes.

We can then see a spectrum of criteria necessary to be considered a *shoteh* present in the tradition, ranging from very restrictive (that is, the person must exhibit a very high level of abnormal behavior to be declared incompetent) to quite broad (that is, a relatively small deficiency in mental capacity renders one incompetent).

As one inclines towards the more restrictive end of the spectrum, the criteria to be considered incompetent grow more difficult to meet. In the language of modern ethics, we can see an increasingly higher value on personal autonomy. As one inclines towards a more broad definition of the *shoteh*, more and more people are assessed to be legally incompetent. We can say then that autonomy is given less value, and more weight is put on beneficence – protecting one's health and well-being.

However, the overlap between the classical Jewish positions and the modern ethical debate is not necessarily so smooth. It may be that the reasons why certain decisors inclined towards a more

¹⁰ As cited in *Beit Yosef, Even Ha'ezer* 119.

¹¹ Maimonides, *Mishne Torah, Hilchot Edut* 9:9.

restrictive ruling (legal opinions which through our modern lens initially appear to give a higher priority to individual autonomy than to beneficence) may not have been motivated by a concern for individual autonomy at all. To the contrary, they may have been decisions asserting the priority of beneficence. For example, in the cases before Rabbis Simcha of Speier and Avigdor HaCohen, the issue was whether a man who had given a divorce document to his wife, was legally competent to do so. Had they set a lower standard to declare incompetence and decided that the man was not legally competent, the woman would have remained married in the unbearable position of an *agunah*. We must entertain the possibility that their legal analyses may be heavily influenced by the pressing needs of the woman before them and that their rulings, despite their appearances, were not intended to acknowledge the husband's right to make autonomous choices, but rather were benevolently intended to avoid harming the woman.

With this in mind, it is certainly possible to read the weight of Jewish tradition as leaning towards beneficence, demanding that we intervene in certain situations to protect the health and welfare of someone unable or unwilling to care for ones self, even when such an intervention entails a violation of personal autonomy. On the other hand, it is necessary to note that even the broader position presented in the Talmud, Rabbi Yochanan's position which I labeled as "middle ground" above, would exclude from the category of *shoteh* most elderly people with dementia today. Very few elderly people sleep in graveyards, tear their clothes, or knowingly destroy their possessions. Only a fraction more wander alone at night. The Talmud then seems reluctant to classify people in the situation before us as mentally incompetent. This dovetails well with the trend of modern legal decisors to exempt more and more people from the category of the *shoteh*.¹²

The *shoteh* is exempt from the mitzvot and free from punishment for most actions, including even murder according to the *Mechilta*.¹³ Thus, by declaring a person not to be a *shoteh*, a

¹² Rabbi Eliezer Waldenberg, for example, separates out the developmentally disabled (*peti'im*) from the category of the *shoteh*, even though they may exhibit many similar mental deficiencies. See *Tzitz Eliezer* 14:69.

¹³ See *Chagiga* 2b; Rashi to *Chagiga* 3b, s. v. *eizehu shoteh*; *Pri Megadim*, introduction to 2:2; and *Mechilta, Mishpatim* 4.

Jewish court keeps that person integrated into the community by demanding that basic obligations of worship, study, charity, and other social responsibilities be upheld. While the person's mental processes may not be functioning at the highest capacity possible, that person's status as a living human being with a connection to his or her community and to God is affirmed. It should not surprise us that Maimonides holds the broadest definition of who should be classified as a *shoteh*, because in his own theology *koach ha-sichli* – the capacity for rational thought – characterizes the apex of human existence. This is not universally accepted though. The other voices in this discussion seem to be asserting that it is the *neshamah* – the soul – which marks the nexus point between us and God. A person with reduced mental capacity certainly still has a soul, and some modern scholars suggest that such a person may have even more profound access to the soul than many other human beings. Following this interpretation, we do not see a formal argument for individual autonomy *per se*, but we do see a strong effort to caution against overzealously dismissing a person's expressed wishes for the sake of imposing what an outsider believes to be a preferable plan of action.

If we err too far on the side of beneficence in this delicate balance, Jewish tradition reminds us that we risk robbing a person not only of his or her autonomy, but also of his or her humanity as expressed through the ability of a person, created in God's image, to make essential choices about how to live. Modern medical ethicists and Maimonides remind us, however, that if we err too far in preserving that autonomy we risk failing to meet our obligation to protect vulnerable human beings who depend on others for their health and well-being.

A Sliding Scale of Competence

One way to better manage this difficult balance of competing plans of care is to envision a sliding scale for necessary levels of competence. In this model, decisions with more at stake for the person with dementia demand that the person demonstrate a higher level of decision-making capacity in order that his or her stated preferences override those of physicians, family members, or other caregivers when they conflict in creating a plan of care. The Court of Appeal in the United Kingdom has established this principle in formal legal precedent holding:

What matters is that the doctors should consider whether at the time the person had a capacity which was commensurate with the gravity of the decision. The more serious the decision, the greater the capacity required.¹⁴

The advantage of such a system is that, if instituted effectively, it allows us to respect a person's autonomy in as many situations as possible, without allowing what others consider to be the most extreme hazards to persist. Most parents, Mark Wicclair notes, institute a similar sliding-scale in raising their children; they are likely to allow a five year-old to choose whatever he wants to eat from the menu unless one of those items threatens the child's health.¹⁵ While I am always leery of drawing parallels between children and the elderly too closely, it is important to note that we intuit this sliding-scale approach in many different settings.

The primary disadvantage to a sliding-scale approach is that we increase the margin for error and permit unnecessary instances of "false-positives" – people mistakenly declared to be incompetent to make certain important decisions. As Alec Buchanan notes, instead of avoiding harm, we inflict the harm, which follows from a person's autonomous wishes not being respected.¹⁶ In so doing, we act in exactly the way which the Jewish legal tradition seems to caution against so strongly; objectifying, depersonalizing, and alienating the elderly person with dementia.

Consequently, if we are to pursue this model, we must proceed with extreme care in assessing and reassessing competence in order to reduce the number of situations where we mistakenly dismiss a person's decision about his or her care. While it is not within the scope of this paper to evaluate existing or to propose new scales of assessment, the six-part definition of decision-making capacity which I detailed above could serve as the basis for a multi-faceted assessment model. Each aspect of capacity should be measured individually in order to avoid a simple determination of competent or incompetent; instead, one could present a complex evaluation for each area of a person's decision-making capacity. As more aspects of decision-making capacity are functioning well, caregivers

¹⁴ *Re T* [1992] 4 All E. R. 649.

¹⁵ Wicclair, M., "Patient Decision-making Capacity and Risk", *Bioethics*, 1991; 5:91-104.

¹⁶ Buchanan, A., "Mental Capacity, Legal Competence and Consent to Treatment", *Journal of the Royal Society of Medicine*, 2004; 97: 415-420.

would be inclined to accept that person's decisions in more and more serious matters, even when they conflict with the wishes of those same caregivers. Accordingly, a person's autonomous decisions would be respected in the maximal number of situations, while reducing the number of situations where a person with dementia's impaired decision-making capacity leads to serious harm.

Regardless of the specific method for assessment employed, it is obligatory to assess decision-making capacity in an environment where the person with dementia is best able to function. This would include ensuring that the person feels comfortable in the physical space and with the people present, delivering the information about possible options in non-technical language with the person having as many opportunities as necessary to ask questions, assessing capacity at the time of day when the person is highest-functioning, and taking care that the person is not impaired by medications when the assessment is made. Assessments must be repeated over time and yield consistent results to stand as sufficiently reliable to warrant overriding a person's decision about his or her care.

How Should Decisions Be Made When Others Must Make Them?

Once a determination is made that a person with dementia is not competent to make a specific decision, we must consider who should make the decision on his or her behalf, and what values that person or persons should prioritize in making that decision. In the American legal model, a person, while still legally competent, has the right to appoint a surrogate decision-maker. In the absence of such an appointment, consent for treatment decisions is usually sought from close family members, and most states have codified a next-of-kin order for decision-makers. A physician or other clinician functioning *in loco parentis* is rightly considered by most ethicists to remain a last resort only in emergency situations when no relative or guardian is available to make an important treatment decision on behalf of the mentally-impaired person.¹⁷

While this hierarchy for decision-making of

¹⁷ Larkin, G., Marco, C., and Abbott, J., "Emergency Determination of Decision-making Capacity: Balancing Autonomy and Beneficence in the Emergency Department", *Academic Emergency Medicine*, 2001; 8: 282-4.

- 1) Patient
- 2) Patient-appointed surrogate
- 3) Next-of-kin
- 4) Clinician

represents a sufficient model when consensus is generally present about a given plan of care, it often breaks down in practice, when family members disagree with each other or with medical staff about the best plan of care. Leaving courts as a last resort, many hospitals and other institutions will defer to the judgment of an ethics board which gathers professionals from different fields, often including clergy. This solution seems most consistent with the general Jewish notion that the obligation to protect and care for any vulnerable person does not fall exclusively on that person's next-of-kin but more generally on the entire community. The Chatam Sofer accepts this principle so thoroughly that, in one case, he permits a father to banish his mentally impaired adult-daughter from the home, arguing that the father bears no greater responsibility to provide for her care than does anyone else in the community.¹⁸ Certainly, the best way to ensure that a person's autonomy is respected, even after dementia impairs cognitive-function, remains to appoint a surrogate who he or she trusts to make decisions at a later time, and then to discuss the values to which the surrogate should give priority when making those decisions. The next-best option, following Jewish tradition, would be a more broad communal decision – in most cases, best represented by an experienced ethics-board – which takes into account the needs and preferences of the next-of-kin but does not give them priority to the exclusion of other concerns. Sadly, fear of litigation and pressure from insurance providers generally makes this option less viable in current American culture; undue weight is often afforded, in making these decisions, to the people most likely to sue.

Whoever ends up bearing final responsibility for the decision must consider how best to make that decision. Often, in this situation, two competing values emerge: what seems best for the person at the time and what seems most consistent with the person's previously stated wishes. As the degree of ambiguity

¹⁸ Chatam Sofer, *Y.D.* 2:75

increases about either variable, the question grows only more cloudy. However, even when one is fairly certain that the decision best representing each option is known, it is difficult to weigh one against the other. Given the strong argument I made above for respecting individual autonomy, I am inclined to give priority in this conflict to carrying out what we believe to be most consistent with the person's prior beliefs and values. However, we all know people who, when seeing others with dementia, say, "I would never want to live like that!" Nevertheless, in my work as a chaplain, I have engaged with many people who thrive in the midst of their dementia and are able to appreciate their present reality in ways they often could not have previously. What might have happened if the situation arose where someone making decisions on someone else's behalf had acted on a prior statement of "I could never live like that" and ended the person's life too early?

Addressing this concern, Rebecca Dresser and Peter Whitehouse suggest the standard of trying to determine what it is like to be that particular person at that time and make treatment decisions from such a perspective. They term this approach the "objective treatment standard" which seeks to identify the basic features of conscious experience that affect human welfare. In essence, its goal is to ascertain which treatment option would be preferable from the patient's point of view. It focuses on the incompetent patients' current condition (as opposed to prior preferences), and requires an evaluation of the benefits and burdens that administering or forgoing treatment would entail for that particular patient.¹⁹

While this represents an incredibly valuable exercise in which any family member or caregiver should engage prior to making decisions on someone else's behalf, it carries with it the danger that the final decision will reflect more of the decision-maker's biases than the patient's actual status. Studies show that physicians and others are likely to underestimate elderly people's quality of life (with and without dementia) as compared to the people's own ratings.²⁰ This attests to just one of the many faulty assumptions

¹⁹ Dresser R., and Whitehouse, PJ, "The Incompetent Patient on the Slippery Slope", *Hastings Center Report*, 1994; 24:6-12.

²⁰ Starr, TJ, Pearlman, RA, and Uhlmann, RF, "Quality of Life and Resuscitation Decisions in Elderly Patients", *Journal of Geriatric Internal Medicine*, 1986; 1:373-9.

which the decision-maker might be holding as he or she tries to step into the mind of the person with dementia. The decision in the end, however it is made, will necessarily be subjective; yet, this particular standard allows for so much subjectivity that it carries with it too great a risk that the surrogate's priorities will supplant those of the person for whom the decision is being made.

We revert then to relying on the person's previously stated beliefs and values. In ascertaining them, the person's family and friends who best understand what he or she held dear, stand at a privileged position in the decision-making process. In this model, the obligation rests squarely on each of us, while competent, to communicate as clearly as possible how we envision our values and beliefs manifesting themselves in different scenarios. These conversations might be brutally difficult. It certainly is not easy for a healthy person to speak frankly about dementia, fragility, old-age, and death. However, overcoming that challenge is the price we must pay in order to ensure that our autonomy and values are respected when decisions must be made, and we can no longer make them for ourselves. If we fail, we not only squander the opportunity to live the best life possible through dementia, but we also unfairly burden those who are already grieving our illness with the additional demands of trying to guess what we would prefer, and the nagging second-guessing which will likely persist afterwards as they wonder if they made the right decision.

Looking Forward

This discussion has set out the values and issues in conflict surrounding decision-making for those with dementia. It has not, however, concluded the specifics. Better assessment models need to be created in order to determine levels of decision-making capacity, and models already in use need to be further evaluated. This discussion has generally proceeded on the assumption that sufficient time is available to make the best decision possible. Looking ahead, we will need to consider how to proceed when an emergency decision must be made by a doctor or caregiver, and a formal assessment of capacity is not possible. Consent to participate in research is another area which might demand different standards of competence than the ones discussed above. On the one hand, if more than minimal risk is involved and benefit is not certain, we would expect to require a very high level of

decision-making capacity for consent, and we might permit a surrogate to make such a decision on someone else's behalf in only rare circumstances. On the other hand, if such high standards are required, benefits to future people with dementia might never come. At what point can we violate one person's autonomy on the grounds that he or she is likely to benefit by another? These questions, among others, follow with us as the American population ages, and dementia affects more and more people. It is my hope that this essay will help to guide people trying to answer the questions raised with both a respect for modern ethical insights and for classical Jewish tradition.

Source: **ASSIA – Jewish Medical Ethics**,

Vol. V, No. 2, June 2006, pp. 45-55