Impaired cognition may render individuals vulnerable to physical, financial or psychological harms. Because of this vulnerability, families, physicians and other concerned persons may find themselves in the difficult role of determining what is “right” for a person who appears incapable of making self-regarding decisions. Neurologists are no strangers to this challenge, given their close involvement in the care of demented patients. And the challenge will only become more daunting unless more effective ways or preventing or treating dementias emerge.

In this context, my presentation will focus on ethical issues that may arise in the care of demented patients. Part I will outline elements of an ethics-based approach to the care of vulnerable persons. Part II will consider approaches to implementing ethics-based care for demented individuals. Part III will consider the legal aspects of certain difficult decisions. The goals are to provide an account of ethical and legal principles that inform decisions with respect to demented individuals and to suggest a framework for ethics-based care.

I – Elements of Ethics-Based Care

Several elements underlie ethics-based care of demented individuals:

Respect for autonomy
One consequence of dementia may be a limited capacity to express or indicate preferences concerning matters of great personal significance. Examples of such matters include decisions about where to reside, how to distribute or manage property, whether to drive, whether to agree to pharmacological or surgical treatments, whether to participate in clinical research, whether to authorize a “do not resuscitate” order, or whether to decline other life-prolonging measures. To the extent it is possible to discern the preferences of a demented individual, the principle of autonomy - or right of self-determination - obligates neurologists or other caregivers to take such preferences into account. Ascertaining preferences may require thorough assessments of mental status, extended observation, and interviews with family or other lawful surrogates. In cases where dementia is severe or language functions are greatly impaired, it may be impossible to identify an individual’s preferences. And if family or other surrogates offer little or no input, the thrust of the autonomy principle in decisions about care or treatment is greatly attenuated.

Respect for Humanity
Some demented individuals are incoherent, uncomprehending, irritable, incontinent and non-compliant, singly or in combination. These behaviors can test a physician’s commitment to the role of caregiver and the temptation to avoid or distance oneself from such patients can be strong [1]. Yielding to this temptation can result in inadequate evaluations, failure to provide the most effective and timely treatments, and failure to guide families and other caregivers in coping with the personal and financial stresses of caring for demented patients. If physicians set bad examples in caring for their demented patients, they may unwittingly increase the risk of insensitive or abusive care by families or other caregivers. Thus, if presumed leaders of the treatment team exhibit disrespect for demented patients, others on the treatment team may follow suit. Data supporting this speculation are lacking. But instances of inhumane care at home and in residential facilities are not [2]. By showing respect and empathy for their demented patients, physicians can therefore both honor their own ethical obligations and encourage others to respond in similar fashion.

Avoiding Harm
The ethical principle of nonmaleficence holds that a primary obligation of caregivers is to do no harm. One implication of this principle is that decisions concerning demented individuals should be subjected to a risk vs. benefit analysis. In some cases, risks are more amenable to objective assessment (e.g. complications of feeding gastrostomy) than are benefits (e.g. value to demented person of a longer life), and the calculus of what is in the “best interests” of the individual becomes problematic. Applying the concept of “substituted judgment” may be of some help here. It permits observations and opinions of families and other surrogates to be factored in to an
appraisal of how a demented patient would have weighed risks and benefits were he or she hypothetically competent to do so. But it is also important to draw a distinction between an opinion that reflects the personal views of the proxy and one that derives from an informed assessment of what the patient would likely prefer.

**Justice**

Whether a particular decision concerning a demented person is just depends in part on how the decision is reached. To some degree, what is “just” rests in the eye of the beholder. But a decisional process that is transparent, that permits participation by the demented patient to the extent of his or her capacity, that allows for open and full discussion among interested parties, and that takes into account “evidence-based medicine” or other reliable data would seem to satisfy elemental standards of justice. Moreover, if outcome-relevant data or well-designed opinion surveys document a societal consensus on an ethically-sensitive issue, decisions consistent with the consensus will likely be viewed as just. On the other hand, where irrelevant or marginally reliable data are utilized, or decisions are made by physicians without input by lawful or otherwise appropriate proxies, the justice of a particular decision may be suspect. Where decisions raise especially difficult issues (e.g. removal of a feeding tube from a brain-injured but not vegetative patient), institutional ethics committees or ombudsmen may offer useful guidance to physicians and proxies. And in those few cases where disagreements seem intractable and a decision has major consequences for a demented patient, obtaining a judicial ruling may become necessary.

### II – Implementing Ethics-Based Care

**Diagnostic Evaluation**

An essential foundation for ethics-based care of the demented individual is a complete and accurate diagnostic assessment [3]. Potentially reversible conditions (e.g. delirium, depression) must be excluded. The possibility that available therapies may stabilize or even improve cognitive functions should be explored and appropriate treatment provided. The assessment should also include an inventory of what a demented individual can and cannot do (e.g. read, write, recognize family and friends, engage in conversation, dress or feed self, navigate safely about the home, operate a motor vehicle). Once dementia has been fully characterized and appropriate treatments plans have been developed, the focus can then turn to assessment of the individual’s capacity to make self-regarding decisions.

**Assessing Decisional Capacity**

The legal and ethical doctrine of informed consent sets the parameters for assessing decisional capacity. The thrust of the doctrine is that an individual’s consent is informed if there has been full disclosure of material information and if he or she possesses capacity to understand the disclosure. Assuming adequate disclosure, the consent itself must be voluntary. As interpreted by the courts, “material” information is that which would influence a decision as to whether or not to agree to a treatment or procedure. Among U.S. courts, a doctrinal difference exists as to whether what is “material” turns on the perception of the individual (the “subjective” standard) or that of a hypothetical “reasonable” person (the “objective” standard) [4]. Consent is presumed to be voluntary if the consenting person has decisional capacity and the consent itself is not the product of duress or undue influence.

Most litigation involving issues of informed consent centers on the adequacy of disclosure by physicians or clinical researchers. The emphasis shifts when questions arise as to whether an individual possesses capacity to comprehend a disclosure [5]. If capacity is lacking, even an impeccably clear and complete disclosure will not suffice to generate an informed consent. What counts most is proof that critical elements of the disclosure were comprehended (e.g. that a cholinesterase inhibitor may cause diarrhea, that a feeding gastrostomy will not improve prospects for neurological recovery). And even if such proof can be produced, questions may arise as to whether consent is the product of some sort of cognitive processing. Thus, if an individual merely answers or gestures “yes” or “no” to a treatment or a procedure after it has been described and explained, it may difficult to infer that the answer or gesture reflects understanding. Answers to a series of questions or responses to various factual scenarios may be more informative [6]. If answers are clear and consistent, a conclusion that they derive from an understanding of the disclosure may be justifiable. The practical difficulties of such an approach are obvious, however, and involving a surrogate or proxy in the process is almost always necessary from both legal and ethical perspectives.

**Choice of Proxy**

Proxy decision-makers may come in several guises. Much depends on the decision at issue. If concerns exist about the capacity of a demented individual to manage his or her assets, a guardianship proceeding may be necessary. Here a family member or caregiver could initiate the process by filing a petition with an appropriate
court, some form of hearing would be held at which proof of the individual’s capacity is presented, and the court would appoint guardian or conservator manage the assets. The designated guardian or conservator could be a family member, a bank or an appropriately trained individual. A guardianship could also be expanded to cover other matters, including a formal determination that the person is incompetent to manage property, obtain or consent to medical care, reside in the home, or operate a motor vehicle. In this respect, modern guardianship laws encourage flexible arrangements. They tend to permit as much freedom from legal and other constraints as is feasible without compromising health or safety [7].

Short of formal guardianship, state laws generally permit designated family members or other lawful surrogates to act on behalf of persons who lack decisional capacity (e.g. ability to give informed consent to risky but medically necessary care). These laws also protect physicians and other caregivers from liability if they rely on consents such designees have given. If a decision has ethically-sensitive overtones (e.g. consent to DNR order or removal of feeding tube), explicit statutory protection may not be available unless a demented individual had, before becoming incapacitated, appointed an agent who is expressly empowered to consent to such a decision. A New York statute [8], for example, allows a duly appointed agent to consent to a DNR order on behalf of a legally competent patient if the attending physician determines the patient “would suffer immediate and severe injury from a discussion of cardiopulmonary resuscitation.” Where a demented individual had not appointed such a agent before becoming legally incapacitated, there is no statutory immunity. Judicial rulings, however, indicate that proxy authorization of DNR orders is lawful with respect to patients with severe and irreversible brain injury [9].

Complex legal issues may arise with respect to decisions about withdrawing ongoing life-support. Several judicial decisions have held that it is lawful to remove life support from individuals in chronic vegetative states - but only if there is convincing proof that removal is consistent with preferences such individuals expressed while competent [10]. The most convincing proof would be an advance directive that specifically addresses the situation at issue. But courts have relied on other forms of proof, such as explicit conversations with family or friends, to reach a conclusion that removal of life support comport with the competently expressed preferences of one who subsequently entered a vegetative state [11]. Courts have not, however, sanctioned removals of life support from severely impaired but not vegetative persons where convincing proof of their preferences is lacking or unconvincing. In other words, severe and progressive dementia, standing alone, is not a legal justification for removing life-support – even if a lawful proxy is personally convinced that removal is the right choice.

Planning Care
From the preceding discussion, it is apparent that well-formulated advance directives can both guide families, other proxies and caregivers in determining appropriate levels of care and offer protection against legal and ethical challenges to their conduct.

Advance directives can take various forms. One is a “living will” that spells out how the drafter wishes to be treated if decisional capacity is lost. Another is a “durable power of attorney.” It appoints an agent to act on behalf of the drafter in the event he or she becomes incompetent. Unlike a conventional power of attorney which lapses when a person loses legal capacity, the “durable” power endures after competence is lost.

To facilitate use of advance directives, many states have adopted the Uniform Health Care-Decisions Act (UHCDA) [12]. Section 2 of this law authorizes appointment of an agent “to make any health-care decision the principal could have made while having capacity.” Unless otherwise specified, the appointment takes effect “only on a determination that the principal lacks capacity.” Determinations with respect to capacity “must be made by the primary physician.” The agent must make health-care decisions “in accordance with the principal’s individual instructions, if any, and other wishes to the extent known to the agent.” Otherwise, “the agent shall make the decision in accordance with the agent’s determination of the principal’s best interest.” In making this determination, “the agent shall consider the principal’s personal values to the extent known to the agent.”

The federal Patient Self-Determination Act [13] complements the UHCDA. It requires health care facilities that serve beneficiaries of federal health programs (virtually all health care facilities) to furnish patients with information about their rights under state law, “including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives.” The statute also commands these facilities “to ensure compliance with requirements of State law (whether statutory or as recognized by the courts of the State) respecting advance directives…”
Although these laws validate advance directives as tools for managing the care of demented individuals, their impact remains to be determined. For various reasons - or non-reasons - many persons do not execute advance directives or otherwise engage in substantive discussions of how they want to be managed if they become demented. Even if they do, written directives or other information may not be made available to health care providers in a timely way. And the documents themselves may fail to provide specific guidance to proxies or caregivers as to what levels of care to provide or when to stop care. With growing societal appreciation of the burden of dementia in an aging population, the situation may change. Neurologists, in particular, can play an important role here by encouraging patients and their families to consider advance directives, or at least to begin thinking about what kind of care they would prefer in the event of irreversible mental incapacity.

End of Life Care
Some of the more taxing problems surrounding end-of-life care for demented patients could surely be resolved by artfully drawn advance directives. Short of this circumstance, proxies and caregivers are left with working out an agreement on what is in the best interests of the demented individuals. If they agree that stopping or reducing the intensity of life supporting measures is the preferred option, they may wish to consult with religious advisers, ethics consultants and legal advisers before acting. Although medical and ethical considerations should seemingly trump legal considerations in this situation, state laws or regulations and institutional policies may constrain actions such as removal or withholding of feeding tubes.

An illustrative cautionary tale is the decision of the New York Court of Appeals in Matter of Westchester County Medical Center (O’Connor) [14]. The case involved a minimally conscious patient who had sustained multiple brain infarcts. She did not have an advance directive. Her attending physician and a consultant agreed it was unlikely she would improve but the attending physician nevertheless recommended a feeding tube. When her two adult daughters objected, the hospital sought a court order authorizing placement of the tube. At a court hearing, evidence was introduced concerning the patient’s past conversations with family and friends in which she had indicated a desire not to receive life support if she had a condition that would make her a burden and from which she could not recover. The state’s high court sided with the hospital because it was not convinced that the patient held a “firm and settled commitment to the termination of life supports under the circumstances like those presented.” In other words, even if dementia is severe and irreversible, withholding a feeding tube may generate legal problems if it cannot be shown unequivocally that this comports with an individual’s wishes.

Clinical Research
Coupled with intensifying research into the biology of dementia and into developing new therapies comes a growing need to conduct clinical research in demented subjects. The research may have a therapeutic dimension, such as determining the safety and efficacy of a new drug or other biological agent (e.g. vaccine, monoclonal antibody). But other studies will be more purely scientific, such as identifying a relevant biomarker, mutant gene or protein, or a distinctive abnormality on functional neuro-imaging. Risks and degrees of intrusiveness may vary from minimal to substantial. And in virtually every case, questions will arise as to whether a demented individual can, either personally or by proxy, lawfully agree to participate in such research. The exceptions may be purely observational studies or where a potential participant had, while competent to do so, executed an advance directive that plausibly covers the type of research at issue.

Conduct of research in the United States is generally subject to federal regulation [15]. Particular regulations specify procedures for obtaining informed consent and mandate review and monitoring by Institutional Review Boards (IRBs). In the context of these regulations, demented individuals fall into the general category of vulnerable subjects (i.e. persons at risk for undue influence or duress). As to them, IRBs are enjoined to develop “additional safeguards” (not otherwise specified) to insure that their consent is informed. The informed consent may be obtained from a “legally authorized representative” (also not otherwise defined) where a potential participant lacks capacity to consent. In the case of a demented subject, an IRB will ordinarily require that the proxy provide a consent that satisfies regulatory standards and that, to the extent feasible, the assent of the demented person also be secured. At the center of current debates about research in demented subjects is whether a proxy can lawfully consent to research that presents a greater than “minimal” risk to a vulnerable participant [16], or to research that is not designed to demonstrate clinical efficacy for the subject (e.g. a Phase I safety trial of a new cholinesterase inhibitor). In circumstances where the research is deemed clinically or scientifically important, where discernible risks are more than minimal, and doubts exist about whether proxy consent is lawful, obtaining advance judicial approval may be essential. Such an approval might also establish a precedent applicable to research proposals that raise analogous issues.
Examples drawn from various legal scenarios serve to illustrate how core ethical principles of autonomy, beneficence and justice influence the outcomes of difficult or controversial cases.

Constraints on Liberty
Some demented individuals act in ways that put themselves or others at risk of harm. Examples include driving a car or motorcycle and behaving violently. In these circumstances, caregivers or others may initiate proceedings to revoke the person’s license to drive or to bring about a civil commitment. Such actions clearly threaten the liberty or autonomy of the demented person. The question then becomes whether the constraints on liberty can be justified.

Some demented individuals retain sufficient motor or sensory skills to manage the mechanics of driving. But because of impairments of orienting capacity, visuospatial integration, reaction times, or judgment, they present a heightened risk of accidental harm to self or others. If they have enough insight to recognize the risk, or if family members or others can induce them to relinquish driving, formal legal or regulatory actions can be avoided. However, if they resist, such actions may be necessary. Drivers’ licensing is the responsibility of individual states, and procedures for revoking licensure vary considerably. The situation is further complicated by differences in reporting requirements. For example, some states require licensees themselves to report specified conditions that are thought to threaten driver safety (e.g. epilepsy). Other states assign this responsibility to physicians, and include dementia as a reportable condition [17]. Moreover, dementia itself is not generally viewed as a reportable condition. Also, while states can constitutionally exercise “police power” in regulating highway safety, their laws are subject to constitutional challenge if they are not “rationally related” to the goal of promoting highway safety. Application of such laws to the facts of a particular case can also be challenged. Thus, if counsel for a demented individual produces evidence that a class of drivers (e.g. adolescent males) lawfully entitled to licensure poses a greater actual risk to highway safety than does a demented person, counsel may have two arguments available. One is that the law as applied to the demented individual is unconstitutional. The second is that there is no fact-based justification for applying the law to the demented person.

Demented individuals who behave violently may be subject to civil commitment. The U.S. Supreme Court has upheld the constitutionality of civil commitment where there is proof of mental illness and danger to self or others [18]. To satisfy constitutional standards, such proof must be “clear and convincing” – more stringent than the “more probable than not” standard that prevails in civil litigation and less stringent than the “beyond a reasonable doubt” standard of the criminal law. Dementia clearly qualifies as a mental illness. So the focus would ordinarily be on whether the risk of future danger to self or others justifies the denial of liberty inherent in civil commitment. Given widespread concerns about the reliability of predictions of future violence, a court may require a showing that the person has in fact behaved violently on several occasions or that aggressive behaviors have been steadily escalating. Proof of this sort would underscore the justice of abridging the person’s liberty.

Proxy Decision-Making
Assuming dementia has progressed to the point where an affected person has lost capacity for autonomous choice, paramount concerns are identifying an appropriate proxy and determining what authority the proxy can exercise. As previously observed, an advance directive can allay these concerns, especially if it is explicit and detailed. Otherwise, courts may be called on to designate a proxy and determine the scope of the proxy’s authority. In performing this function, courts may need to balance the patient’s “best interests” against the interests of a state in protecting its citizens and reach a decision that accommodates potentially disparate interests.

An illustrative judicial decision is Matter of Conroy [19]. In this case, the proxy was the only surviving relative (nephew) of a demented elderly nursing home resident. In his capacity as her lawful guardian, he sought removal of her feeding tube. She had no advance directive. At the time of the request, she was unresponsive to verbal stimuli, minimally responsive to noxious stimuli, incontinent, had gangrene of her left leg, and had a life expectancy of less than one year. The nephew believed she would not have consented to the feeding tube had she been competent when it was placed. A court-appointed guardian ad litem opposed removal of the tube. The court determined that the nephew could not exercise a substituted judgment on her behalf because evidence was insufficient to show what her preference would be. However, it concluded that a best interests standard would be appropriate. Under this standard, the tube could be withdrawn on proof that the “net burdens of the patient’s life with the treatment…clearly and markedly outweigh the benefits that the patient derives from life.” The court
emphasized that an important element of the calculus is the burden resulting from any pain the patient is experiencing. Thus, to quote the New Jersey court:

“...[T]he recurring, unavoidable and severe pain of the patient's life with the treatment should be such that the effect of administering life-sustaining treatment would be inhumane. Subjective evidence that the patient would not have wanted the treatment is not necessary under this pure-objective standard. Nevertheless, even in the context of severe pain, life-sustaining treatment should not be withdrawn from an incompetent patient who had previously expressed a wish to be kept alive in spite of any pain that he might experience.”

The court rejected the notion that any weight should be attached to opinions of proxies, judges or other third parties about the value of the patient's impaired life. Because the patient had died during the course of the litigation, the best interests standard the court articulated was not actually applied.

**Withholding or Terminating Treatment**

The landmark Supreme Court case of *Cruzan v Director* [20] exemplifies application of the autonomy principle in a dispute over removing life support. In this case, parents of an adult child in a vegetative state sought removal of her life supporting respirator. They proposed to exercise a substituted judgment on her behalf in their capacity as parents. The state of Missouri opposed the request, invoking a state law requiring that proof of a preference for removal of life support must be clear and convincing. The Supreme Court held that the constitutional right of privacy (liberty) includes the right of a person in a chronic vegetative state to direct removal of artificial hydration and nutrition. However, the Court agreed with the state that the right is exercisable only on clear and convincing proof that removal is consistent with preferences expressed during sentient life. Thus, Chief Justice Rehnquist wrote that a “state may properly decline to make judgments about the ‘quality’ of life that a particular individual may enjoy, and simply assert an unqualified interest in the preservation of human life to be weighed against the constitutionally protected interests of the individual.” Since Ms. Cruzan had no advance directive and evidence before the Court as to her preferences was inconclusive, the Court rejected the parents’ asserted authority to exercise a substituted judgment. It then remanded the case for further evidence-gathering. The new evidence satisfied the clear and convincing standard, and her autonomy-based preference for removal of life support was carried out.

**Physician-Assisted Suicide**

Confronted with a diagnosis of irreversible dementia, some individuals may consider the option of suicide. A few may actually attempt suicide using means at their disposal. An even smaller number may seek assistance from physicians in implementing a choice to end their lives. From the perspective of a demented person, the choice for suicide may be perceived as an expression of autonomy. But from the perspective of law, little respect is due this sort of liberty – even if the individual is assumed to be competent to express a preference for death. The Supreme Court has held that there is no constitutionally protected right to control the timing and manner of one’s death [21,22]. Thus, state laws that criminalize physician assisted suicide do not infringe a constitutional right of self-determination. Even under the Oregon Death with Dignity Act, an illness must be “terminal” and “produce death within six months before a physician who assists suicide can claim statutory immunity from prosecution or civil suit [23].

**Participation in Research**

Rules governing clinical research in vulnerable subjects emphasize stringent application of principles of informed consent [24]. In this respect, the rules reflect strong respect for the autonomy of potential subjects. However, where potential subjects lack capacity to provide an informed consent, the autonomy principle holds less sway and the issue becomes whether applying a “best interests” standard is appropriate. In the context of research, use of this standard would require attention to whether the benefits of participation outweigh the risks. Additionally, the question arises as to whether cognizable benefits are limited to those which are designed to benefit the individual subject, or extend to include acquisition of new information about a participant’s disease or condition. Thus, for a demented subject, is the only cognizable benefit the potential that the research will improve the subject’s dementia? Or is it also in the “best interests” of the subject if the research is designed only to gather new information about dementia of the type affecting the patient, or only to assess the pharmacokinetics or safety of a drug that is being considered for treating such a dementia? In other words, must the benefit be directly therapeutic to justify inclusion in a risk vs. benefit calculus?

*Grimes v Kennedy Krieger Institute* [16] illustrates one judicial response to questions of this sort. The research at issue was designed to compare different methods of lead abatement in urban housing units. As part of the study, ambient lead levels were measured periodically, as were blood lead levels in children residing in the units.
Consent was obtained from persons residing in these units, including parents of resident children. The informed consent document stated that participants would be informed in a timely fashion of the results of testing. Litigation resulted after two parents learned that their children had elevated blood lead levels and that there had been a delay in reporting elevations in ambient lead levels in their units. The children apparently showed no evidence of lead toxicity. The trial court granted summary judgment to the defendant research institute. The Maryland appeals court overturned this ruling in an opinion that was highly critical of the defendant research institute. It characterized the research as a “non-therapeutic” study that put vulnerable subjects (i.e. children) at risk of harm, and held that the parents could not lawfully consent to their participation in such risky research.

The implication of this ruling is that proxies of vulnerable research subjects cannot provide a lawfully effective consent to non-therapeutic research that is more than minimally risky. If widely followed, the ruling would allow a “best interest” calculus only as to research that is designed to offer a therapeutic benefit to participants in the research. It is of interest that the defendant had suggested that the research offered “therapeutic” benefit to the children in learning whether safe housing alone is sufficient to keep blood levels in an acceptable range. The court, however, interpreted this argument as indicating an effort by the defendant’s IRB avoid federal regulations designed to protect children from non-therapeutic research. In commenting about the role of an IRB the justice who authored the majority opinion observed that IRBs “are not designed, generally, to be…[as] concerned with the ethicality of the experiments they review as they are with the success of the experiments…The conflicts are inherent…”

While not addressing the issue of consent to research in children, a research advance directive could enable more than minimally risky research in demented adults. The directive must be executed before decisional capacity is lost and should specify what type of research is agreed to. For example, if a directive is prepared by a legally competent adult with early Alzheimer disease it should explicitly state whether the consent covers only therapeutic research - that is, research designed to determine the efficacy of a treatment for the benefit of the participant - or whether it also covers research designed to generate scientific knowledge about Alzheimer disease or the safety of a particular treatment for persons with Alzheimer disease. The validity of any such research advance directive would be seriously compromised if its preparation was encouraged or facilitated by a physician who is might also be an investigator under the relevant research protocol.

References

8. New York Civil Law, Article 29-B, section 2964(3)(a)


13. United States Code Annotated, section 1395cc

14. Matter of Westchester County Medical Center (O’Connor), 72 NY 2d 517 (NY Ct App 1988)


16. Grimes v Kennedy Krieger Institute, 782 A 2d 807 (MD Ct App 2001)


20. Cruzan v Director, 497 US 261, 110 S Ct 2841 (1990)


23. Oregon Death with Dignity Act, section 1.01(12)

Ethical Issues in Dementia

Key Points

Elements of Ethics Based Care

- Respect for Autonomy: To the extent it is possible to discern the preferences of a demented individual, the principle of autonomy obligates neurologists and other caregivers to take such preferences into account.
- Respect for Humanity: By showing respect and empathy for their demented patients, physicians can therefore both honor their own ethical obligations and encourage others to respond in similar fashion.
- Avoiding Harm: A primary obligation of caregivers is to do no harm. Decisions concerning demented patients should be subjected to a risk vs. benefit analysis.
- Justice: A decisional process that is transparent, that permits participation by the demented patient to the extent of his or her capacity, that allows for open and full discussion among interested parties, and that takes into account “evidence-based medicine” or other reliable data would seem to satisfy elemental standards of justice.

Implementing Ethics-Based Care

- Assessing Decision Capacity: An individual’s consent is informed if there has been full disclosure of material information, and if he or she possesses the capacity to understand the disclosure. If capacity is lacking, even an impeccably clear and complete disclosure will not suffice as informed consent.
- Choice of Proxy: Short of formal guardianship, state laws generally permit designated family members or other lawful surrogates to act on behalf of persons who lack decision making capacity.
- Planning Care: Well-formulated advance directives can guide families and caregivers in determining appropriate levels of care, and offer protection against legal and ethical challenges to their conduct. Neurologists can plan an important role by encouraging patients and their families to consider advance directives.
- End of Life Care: Although medical and ethical considerations ideally should guide these decisions, state laws or regulations may constrain actions such as removal or withholding of feeding tubes if there is not an advance directive.
- Clinical Research: There is current debate over research involving demented subjects and whether their proxy can lawfully consent to research that presents a greater than “minimal” risk to a vulnerable participant.
- Constraints on Liberty: Demented patients who drive may have an increased risk of accidental to themselves or others. Some states require or permit physicians to report such patients to the licensing authority, and other states place this responsibility on the patient. Family members can often be recruited to restrict a demented person’s driving or to remove the automobile or keys.
- Withholding or Terminating Treatment: The Supreme Court has ruled that the constitutional right of privacy includes the right of a person in a chronic vegetative state to direct the removal of life supporting therapies. The Court has also ruled that states may set the standard of proof of the patient’s preferences necessary before such an action is permissible.