We turn finally to what might be the saddest of the tragedies we have been reviewing. We must consider the autonomy and best interests of people who suffer from serious and permanent dementia, and what the proper respect for the intrinsic value of their lives requires. The most important cause of dementia is Alzheimer's disease, a progressive disease of the brain named after a German psychiatrist and neuropathologist, Alois Alzheimer, who first identified and described it in 1906. Patients in the late stages of this disease have lost substantially all memory of their earlier lives and cannot, except periodically and in only a fragmented way, recognize or respond to other people, even those to whom they were formerly close. They may be incapable of saying more than a word or two. They are often incontinent, fall frequently, or are unable to walk at all. They are incapable of sustaining plans or projects or desires of even a very simple structure. They express wishes and desires, but these change rapidly and often show very little continuity even over periods of days or hours.

Alzheimer's is a disease of physiological deterioration. Nerve terminals of the brain degenerate into a matted plaque of fibrous material. Though researchers have expressed some hope that treatment can be developed to slow that degeneration, no such treatment has yet been established, and there is apparently little prospect of dramatically reversing very advanced brain deterioration. A specialist describes the degeneration as occurring “gradually and inexorably, usually leading to death in a severely debilitated, immobile state between four and twelve years after onset.” But according to the US Office of Technology Assessment, death may be delayed for as long as twenty-five years.

Our discussion will focus only on the disease's late stages. I shall not consider, except in passing, the present structure of legal rights and other provisions for demented or mentally incapacitated people, or the present practices of doctors and other custodians or officials who are charged with their care. Nor shall I attempt any report of the recent research into genetic and other features of such diseases, or into their diagnosis, prognosis, or treatment. All these are the subjects of a full literature. I will concentrate on the question of what moral rights people in the late stages of dementia have or retain, and of what is best for them. Is some minimum level of mental competence essential to having any rights at all? Do mentally incapacitated people have the same rights as normally competent people, or are their rights altered or diminished or extended in some way in virtue of their disease? Do they, for example, have the same rights to autonomy, to the care of their custodians, to dignity, and to a minimum level of resources as sick people of normal mental competence?
These are questions of great and growing importance. In 1990, the Alzheimer's Association estimated that four million Americans had the disease, and as Alzheimer's is a disease of the elderly, the number is expected to increase as the population continues to age. In 1989, a Harvard Medical School study estimated that 11.3 percent of the American population sixty-five or over probably had Alzheimer's. The estimated prevalence increased sharply with age: 16.4 percent of people between seventy-five and eighty-four were estimated to have Alzheimer's, and a stunning 47.55 percent of those over eighty-five. The incidence of the disease is comparable in other countries. According to the Alzheimer's Disease Society in Britain, for example, 20 percent of people over eighty are afflicted, more than half a million people have the disease, and that figure will rise to three-quarters of a million in thirty years.

Alzheimer's cost is staggering, both for the community and for individuals. Dennis Selkoe, a leading expert on the disease, said in 1991, “The cost to American society for diagnosing and managing Alzheimer's disease, primarily for custodial care, is currently estimated at more than $80 billion annually.” In 1992, the annual cost of nursing home care in the United States for one individual with Alzheimer's ranged from $35,000 to $52,000.

Each of the millions of Alzheimer's cases is horrible, for the victims and for those who love and care for them. A recent book dedicated “to everyone who gives a '36-hour day' to the care of a person with a dementing illness” describes the lives of some of these patients in chilling detail, not just in the final, immobile last stages, but along the way.

Often, Mary was afraid, a nameless shapeless fear…. People came, memories came, and then they slipped away. She could not tell what was reality and what was memory of things past…. The tub was a mystery. From day to day she could not remember how to manage the water: sometimes it all ran away, sometimes it kept rising and rising so that she could not stop it…. Mary was glad when her family came to visit. Sometimes she remembered their names, more often she did not…. She liked it best when they just held her and loved her.

Even though Miss Ramirez had told her sister over and over that today was the day to visit the doctor, her sister would not get into the car until she was dragged in, screaming, by two neighbors. All the way to the doctor's office she shouted for help and when she got there she tried to run away.

Mr. Lewis suddenly burst into tears as he tried to tie his shoelaces. He threw the shoes in the wastebasket and locked himself, sobbing, in the bathroom.

When Andrew Firlik was a medical student, he met a fifty-four-year-old Alzheimer’s victim whom he called Margo, and he began to visit her daily in her apartment, where she was cared for by an attendant. The apartment had many locks to keep Margo from slipping out at night and wandering in the park in a nightgown, which she had done before. Margo said she knew who Firlik was each time he arrived, but she never used his name, and he suspected that this was just politeness. She said she was reading mysteries, but Firlik “noticed that her place in the book jumps randomly from day to day; dozens of pages are dog-eared at any given moment…. Maybe she feels good just sitting and humming to herself, rocking back and forth slowly, nodding off liberally, occasionally turning to a fresh page.” Margo attended an art class for Alzheimer’s victims — they all, including her, painted pretty much the same picture every time, except near the end, just before death, when the pictures became more primitive. Firlik was confused, he said, by the fact that “despite her illness, or maybe somehow because of it, Margo is undeniably one of the happiest people I have ever known.” He reports, particularly, her pleasure at eating peanut-butter-and-jelly sandwiches. But, he asks, “When a person can no longer accumulate new memories as the old rapidly fade, what remains? Who is Margo?”

I must now repeat an observation that I have made before: we are considering the rights and interests not of someone who has always been demented, but of someone who was competent in the past. We may therefore think of that person, in considering his rights and interests, in two different ways: as a demented person, emphasizing his present situation and capacities, or as a person who has become demented, having an eye to the course of his whole life. Does a competent person’s right to autonomy
include, for example, the power to dictate that life-prolonging treatment be denied him later, or that funds not be spent on maintaining him in great comfort, even if he, when demented, pleads for it? Should what is done for him then be in his contemporary best interests, to make the rest of his life as pleasant and comfortable as possible, or in the best interests of the person he has been? Suppose a demented patient insists on remaining at home, rather than living in an institution, though this would impose very great burdens on his family, and that we all agree that people lead critically better lives when they are not a serious burden to others. Is it really in his best interests, overall, to allow him to become such a burden?

A person’s dignity is normally connected to his capacity for self‐respect. Should we care about the dignity of a dementia patient if he himself has no sense of it? That seems to depend on whether his past dignity, as a competent person, is in some way still implicated. If it is, then we may take his former capacity for self‐respect as requiring that he be treated with dignity now; we may say that dignity now is necessary to show respect for his life as a whole. Many prominent issues about the rights of the demented, then, depend on how their interests now relate to those of their past, competent selves.¹²

Autonomy

It is generally agreed that adult citizens of normal competence have a right to autonomy, that is, a right to make important decisions defining their own lives for themselves. Competent adults are free to make poor investments, provided others do not deceive or withhold information from them, and smokers are allowed to smoke in private, though cigarette advertising must warn them of the dangers of doing so. This autonomy is often at stake in medical contexts.¹³ A Jehovah’s Witness, for example, may refuse blood transfusions necessary to save his life because transfusions offend his religious convictions. A patient whose life can be saved only if his legs are amputated but who prefers to die soon than to live a life without legs is allowed to refuse the operation. American law generally recognizes a patient’s right to autonomy in circumstances like those.¹⁴ But when is that right lost? How far, for example, do mentally incapacitated people have a right to make decisions for themselves that others would deem not in their best interests?¹⁵ Should Mary, the woman who couldn’t recognize relatives or manage a tub, be allowed to spend or give away her money as she wishes, or to choose her own doctors, or to refuse prescribed medical treatment, or to decide which relative is appointed as her guardian? Should she be allowed to insist that she be cared for at home, in spite of her family’s opinion that she would get better care in an institution?

There may, of course, be some other reason, beyond autonomy, for allowing Mary and other demented people to do as they please. For example, if they are prevented from doing as they wish, they may become so agitated that we do them more harm than good by opposing them, even though the decision they make is not itself in their interests. But do we have reason to respect their decision even when this is not so, even when we think it would be in their best interests, all things considered, to take some decision out of their hands?

We cannot answer that question without reflecting on the point of autonomy, that is, on the question of why we should ever respect the decisions people make when we believe that these are not in their interests. One popular answer might be called the evidentiary view: it holds that we should respect the decisions people make for themselves, even when we regard these decisions as imprudent, because each person generally knows what is in his own best interests better than anyone else.¹⁶ Though we often think that someone has made a mistake in judging what is in his own interests, experience teaches us that in most cases we are wrong to think this. So we do better, in the long run, to recognize a general right to autonomy, which we always respect, than by reserving the right to interfere with other people’s lives whenever we think they have made a mistake.

If we accepted this evidentiary account of autonomy, we would not extend the right of autonomy to decisions made by the seriously demented, who, having altogether lost the power to appreciate and engage in reasoning and argument, cannot possibly
know what is in their own best interests as well as trained specialists, like doctors, can. In some cases, any presumption that demented people know their own interests best would be incoherent: when, for example, as is often the case, their wishes and decisions change radically from one bout of lucidity to another.

But in fact the evidentiary view of autonomy is very far from compelling. For autonomy requires us to allow someone to run his own life even when he behaves in a way that he himself would accept as not at all in his interests. This is sometimes a matter of what philosophers call “weakness of the will.” Many people who smoke know that smoking, all things considered, is not in their best interests, but they smoke anyway. If we believe, as we do, that respecting their autonomy means allowing them to act in this way, we cannot accept that the point of autonomy is to protect an agent’s welfare. And there are more admirable reasons for acting against what one believes to be in one’s own best interests. Some people refuse needed medical treatment because they believe that other people, who would then have to go without it, need it more. Such people act out of convictions we admire, even if we do not act the same way, and autonomy requires us to respect their decisions. Once again, the supposed explanation of the right to autonomy – that it promotes the welfare of people making apparently imprudent decisions – fails to account for our convictions about when people have that right. All this suggests that the point of autonomy must be, at least to some degree, independent of the claim that a person generally knows his own best interests better than anyone else. And then it would not follow, just because a demented person may well be mistaken about his own best interests, that others are entitled to decide for him. Perhaps the demented have a right to autonomy after all.

But we must try to find another, more plausible account of the point of autonomy, and ask whether the demented would have a right to autonomy according to it. The most plausible alternative emphasizes the integrity rather than the welfare of the choosing agent; the value of autonomy, on this view, derives from the capacity it protects: the capacity to express one’s own character – values, commitments, convictions, and critical as well as experiential interests – in the life one leads. Recognizing an individual right of autonomy makes self-creation possible. It allows each of us to be responsible for shaping our lives according to our own coherent or incoherent – but, in any case, distinctive – personality. It allows us to lead our own lives rather than be led along them, so that each of us can be, to the extent a scheme of rights can make this possible, what we have made of ourselves. We allow someone to choose death over radical amputation or a blood transfusion, if that is his informed wish, because we acknowledge his right to a life structured by his own values.

The integrity view of autonomy does not assume that competent people have consistent values or always make consistent choices, or that they always lead structured, reflective lives. It recognizes that people often make choices that reflect weakness, indecision, caprice, or plain irrationality – that some people otherwise fanatic about their health continue to smoke, for example. Any plausible integrity-based theory of autonomy must distinguish between the general point or value of autonomy and its consequences for a particular person on a particular occasion. Autonomy encourages and protects people’s general capacity to lead their lives out of a distinctive sense of their own character, a sense of what is important to and for them. Perhaps one principal value of that capacity is realized only when a life does in fact display a general, overall integrity and authenticity. But the right to autonomy protects and encourages the capacity in any event, by allowing people who have it to choose how far and in what form they will seek to realize that aim.

If we accept this integrity-based view of the importance of autonomy, our judgement about whether incapacitated patients have a right to autonomy will turn on the degree of their general capacity to lead a life in that sense. When a mildly demented person’s choices are reasonably stable, reasonably continuous with the general character of his prior life, and inconsistent and self-defeating only to the rough degree that the choices of fully competent people are, he can be seen as still in charge of his life, and he has a right to autonomy for that reason. But if his choices and demands, no matter how firmly expressed, systematically or randomly contradict one another, reflecting no coherent sense of self and no discernible even short-term aims, then he has presumably lost the capacity that it is the point of autonomy to protect.
Recognizing a continuing right to autonomy for him would be pointless. He has no right that his choices about a guardian (or the use of his property, or his medical treatment, or whether he remains at home) be respected for reasons of autonomy. He still has the right to beneficence, the right that decisions on these matters be made in his best interests; and his preferences may, for different reasons, be important in deciding what his best interests are. But he no longer has the right, as competent people do, himself to decide contrary to those interests.

“Competence” is sometimes used in a task-specific sense, to refer to the ability to grasp and manipulate information bearing on a given problem. Competence in that sense varies, sometimes greatly, even among ordinary, nondemented people; I may be more competent than you at making some decisions and less competent at others. The medical literature concerning surrogate decision making for the demented points out, properly, that competence in this task-specific sense is relative to the character and complexity of the decision in question. A patient who is not competent to administer his complex business affairs may nevertheless be able to grasp and appreciate information bearing on whether he should remain at home or enter an institution, for example.

But competence in the sense in which it is presupposed by the right to autonomy is a very different matter. It means the more diffuse and general ability I described: the ability to act out of genuine preference or character or conviction or a sense of self. There will, of course, be hard cases in which we cannot know with any confidence whether a particular dementia patient is competent in that sense. But we must make that overall judgement, not some combination of judgements about specific task capability, in order to decide whether some mentally incapacitated patient has a right to autonomy. Patients like Mary have no right that any decision be respected just out of concern for their autonomy. That may sound harsh, but it is no kindness to allow a person to take decisions against his own interests in order to protect a capacity he does not and cannot have.

So neither the evidentiary view of autonomy nor the more plausible integrity view recommends any right to autonomy for the seriously demented. But what about a patient’s precedent autonomy? Suppose a patient is incompetent in the general, overall sense but that years ago, when perfectly competent, he executed a living will providing for what he plainly does not want now. Suppose, for example, that years ago, when fully competent, Margo had executed a formal document directing that if she should develop Alzheimer’s disease, all her property should be given to a designated charity so that none of it could be spent on her own care. Or that in that event she should not receive treatment for any other serious, life-threatening disease she might contract. Or even that in that event she should be killed as soon and as painlessly as possible? If Margo had expressed any of those wishes when she was competent, would autonomy then require that they be respected now by those in charge of her care, even though she seems perfectly happy with her dog-eared mysteries, the single painting she repaints, and her peanut-butter-and-jelly sandwiches?

If we had accepted the evidentiary view of autonomy, we would find the case for respecting Margo’s past directions very weak. People are not the best judges of what their own best interests would be under circumstances they have never encountered and in which their preferences and desires may drastically changed. But if we accept the integrity view, we will be drawn to the view that Margo’s past wishes must be respected. A competent person making a living will providing for his treatment if he becomes demented is making exactly the kind of judgement that autonomy, on the integrity view, most respects: a judgement about the overall shape of the kind of life he wants to have lived.

This conclusion is troubling, however, even shockingly, and someone might want to resist it by insisting that the right to autonomy is necessarily contemporary: that a person’s right to autonomy is only a right that his present decisions, not past ones that he has since disowned, be respected. Certainly that is the normal force of recognizing autonomy. Suppose that a Jehovah’s Witness has signed a formal document stipulating that he is not to receive blood transfusions even if out of weakness of will he requests one when he would otherwise die. He wants, like Ulysses, to be tied to the mast of his faith. But when the moment comes, and he needs a transfusion, he pleads for it. We would not think ourselves required, out of respect for his autonomy, to disregard his contemporary plea.
We can interpret that example in different ways, though, and the difference is crucial for our present problem. We might say, first, that the Witness’s later plea countermanded his original decision because it expressed a more contemporary desire. That presumes that it is only right to defer to past decisions when we have reason to believe that the agent still wishes what he wanted then. On that view, precedent autonomy is an illusion: we treat a person’s past decision as important only because it is normally evidence of his present wishes, and we disregard it entirely when we know that it is not. On the other hand, we might say that the Witness’s later plea countermanded his original decision because it was a fresh exercise of his autonomy, and that disregarding it would be treating him as no longer in charge of his own life. The difference between these two views about the force of precedent autonomy is crucial when someone changes his mind after he has become incompetent – that is, when the conditions of autonomy no longer hold. Suppose that the same accident that made a transfusion medically necessary for the Witness also deranged him, and that while still plainly deranged he demands the transfusion. On the first view, we would not violate his autonomy by administering it, but on the second, we would.

Which of the two views about the force of past decisions is more persuasive? Suppose we were confident that the deranged Witness, were he to receive the transfusion and live, would become competent again and be appalled at having had a treatment he believed worse for him than dying. In those circumstances, I believe, we would violate his autonomy by giving him the transfusion. That argues for the second view about the force of past decisions, that view that endorses precedent autonomy as genuine. We refuse to give the deranged Witness a transfusion not because we think he really continues to want what he wanted before – this is not like a case in which someone who objects to a given treatment is unconscious when he needs it – but because he lacks the necessary capacity for a fresh exercise of autonomy. His former decision remains in force because no new decision by a person capable of autonomy has annulled it.

Someone might say that we are justified in withholding the transfusion only because we know that the Witness would regret the transfusion if he recovered. But that prediction would make no difference if he was fully competent when he asked for the transfusion and desperate to live at that moment, though very likely to change his mind again and be appalled tomorrow at what he has done. Surely we should accede to his request in those circumstances. What makes the difference, when we are deciding whether to honor someone’s plea even though it contradicts his past deep convictions, is whether he is now competent to make a decision of that character, not whether he will regret making it later.

Our argument for the integrity view, then, supports a genuine doctrine of precedent autonomy. A competent person’s right to autonomy requires that his past decisions about how he is to be treated if he becomes demented be respected even if they contradict the desires he has at that later point. If we refuse to respect Margo’s precedent autonomy – if we refuse to respect her past decisions, though made when she was competent, because they do not match her present, incompetent wishes – then we are violating her autonomy on the integrity view. This conclusion has great practical importance. Competent people who are concerned about the end of their lives will naturally worry about how they might be treated if they become demented. Someone anxious to ensure that his life is not then prolonged by medical treatment is worried precisely because he thinks that the character of his whole life would be compromised if it were. He is in the same position as people who sign living wills asking not to be kept alive in a hopeless medical condition or when permanently vegetative. If we respect their past requests, as the Supreme Court has decided American states must do, then we have the same reasons for respecting the wishes not to be kept alive of someone who dreads not unconsciousness but dementia.

The argument has very troubling consequences, however. The medical student who observed Margo said that her life was the happiest he knew. Should we really deny a person like that the routine medical care needed to keep her alive? Could we ever conceivably kill her? We might consider it morally unforgivable not to try to save the life of someone who plainly enjoys her life, no matter how demented she is, and we might think it beyond imagining that we should actually kill her. We might hate living in a community whose officials might make or license either of those
decisions. We might have other good reasons for treating Margo as she now wishes, rather than as, in my imaginary case, she once asked. But still, that violates rather than respects her autonomy.

Notes

1. Doctors are now investigating treatments that include reducing the presence in the brain of toxic substances that may play a role in neurodegeneration, enhancing the supply of trophic factors (which facilitate neuronal repair and growth) and neurotransmitters that are missing or deficient in Alzheimer’s patients, and controlling diet-related factors such as blood glucose levels that appear to affect mental functioning in the elderly. See Dennis J. Selkoe, “Aging Brain, Aging Mind,” Scientific American, 135 (September 1992); Robert J. Joynt, “Neurology,” Journal of the American Medical Association, 268 (1992), 380; and Andrew A. Skolnick, “Brain Researchers Bullish on Prospects for Preserving Mental Functioning in the Elderly,” Journal of the American Medical Association, 267 (1992), 2154.


6. In 1992, the continuing Framingham Study determined the prevalence of dementia in its study cohort as 23.8 percent from ages eighty-five to ninety-three. See Bachman et al., “Prevalence of Dementia and Probable Senile Dementia of the Alzheimer Type in the Framingham Study,” Neurology, 42 (January 1992), 42. For a discussion of the differences between the studies cited in this and the preceding note, see Selkoe, “Aging Brain, Aging Mind.”


12. I should mention another great practical problem about the relationship between a demented person and the competent person he once was. Should the resources available to a demented patient depend on what he actually put aside when he was competent, by way of insurance for his own care in that event? Insurance schemes, both private schemes and mandated public schemes, play an important part in the way we provide resources for catastrophes of different sorts. But is the insurance approach the proper model to use in thinking about provision for the demented? That must depend on whether we believe that a competent person has the appropriate prudential concern for the incompetent person he might become, and that in turn depends on knotty philosophical problems about the concept of personal identity. I cannot discuss, in this book, either that philosophical problem or any of the other serious problems about the justice of financing the extraordinarily expensive care of demented patients in different ways. I have discussed both at some length, however, in a report, “Philosophical Problems of Senile Dementia,” written for the United States Congress Office of Technology Assessment in Washington, DC, and available from that office.


15 I am assuming, in this discussion, that it can be in a person’s overall best interests, at least sometimes, to force him to act otherwise than as he wants – that it can be in a person’s overall best interests, for example, to be made not to smoke, even if we acknowledge that his autonomy is to some degree compromised, considered in itself, as against his interests.

16 Buchanan et al., “Surrogate Decision-Making.”

17 There is an important debate in the economic literature on the question whether it can be rational to act against one’s own best interests. The better view is that it can. See, for example, Amartya Sen, “Rational Fools: A Critique of the Behavioural Foundations of Economic Theory,” Philosophy and Public Affairs, 6, no. 4 (Summer 1977).

18 See Buchanan et al., “Surrogate Decision-Making.” Questions of task-sensitive competence are plainly relevant to the issues considered in the Buchanan report. But when the argument against surrogate decision making relies on the autonomy of the demented person affected by these decisions, the overall, non-task-sensitive sense of competence is also relevant.

19 Problems are presented for this judgement of overall integrity capacity when a patient appears only periodically capable of organizing his life around a system of desires and wishes. He seems able to take command of his life sometimes, and then lapses into a more serious stage of dementia, becoming lucid again only after a substantial intervening period, at which time the desires and interests he expresses are very different, or even contradictory. It would be a mistake to say that such a patient has the capacity for autonomy “periodically.” The capacity autonomy presupposes is of necessity a temporally extended capacity: it is the capacity to have and act out of a personality.