

Autonomy and the Demented Self

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CONSIDER THE RIGHTS, NOT OF SOMEONE WHO WAS born and always has been demented, but of someone who was competent in the past. We may think of that person, as the putative holder of rights, in two different ways: as a demented person, in which case we emphasize his present situation and capacities, or as a person who has become demented, in which case we emphasize that his dementia has occurred in the course of a larger life whose whole length must be considered in any decision about what rights he has. We shall have to face a series of problems that seem to contrast, in different ways, the interests of the person conceived in one of these two ways with his interests conceived in the other.

Does a competent person's right to autonomy include, for example, the power to dictate that life-prolonging treatment be denied him later, even if he, when demented, pleads for it? Should what is done for a demented person be in his contemporary best interests, that is, such as to make the rest of his life as pleasant or comfortable as possible? Or in the best interests of the person who has become demented, that is, such as to make his life judged as a whole a better life? (Suppose a demented patient wants care and treatment that would make him a serious burden to other members of his family, and we think that people lead better lives when they are not a serious burden to others. Is it in his best interests, overall, to allow him to become

the burden he is now anxious to be?) Someone's dignity seems connected, in some central way, to his capacity for self-respect. Should we care about the dignity of a dementia patient if he has no sense of his own dignity left? That seems to depend on whether the dignity of a competent person is in some way still implicated in how he is treated when he has become demented. (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 is necessary to show respect for his life as a whole.) Should the resources available to a demented patient depend on what his competent predecessor has actually put aside by way of insurance for his own care in that event, or at least would have put aside if insurance were available on a competitive and realistic basis? 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, as I shall call it, the proper model to use in thinking about provision for the demented? That must depend on whether a competent person has the requisite concern for himself in a later demented stage: whether he has what I shall call a *prudential* concern.

Many of the most prominent issues, then, about the rights of the demented, seem to call for a study of how their interests relate and connect to the interests and decisions of their past competent selves. But every aspect of that claim rests on an assumption I must now acknowledge: that it is *correct* to regard a demented person in the way I said we can, as a person who has become demented. That conception of him supposes that the competent and demented stages of life are stages in a *single* life, that the competent and demented selves are parts of the *same* person. I relied on that assumption in the various suggestions I just made about how the interests and decisions of a competent person might affect his treatment when demented. I assumed, for example, that the control a competent person might seek to exercise over how he is treated when demented is correctly described as autonomy rather than paternalism, that is, that it is the kind of control people seek to have over the course of their own lives. I assumed, in describing the problem raised by beneficence, that it makes sense to treat the different kinds of interests I mentioned—the interest of the demented person in comfort and of the competent person in not being a burden—as competing interests of the same person, so that someone trying to act in that person's best interests would, therefore, have a conflict to

resolve. I raised the question whether a competent person's dignity might be still at stake after he has become demented, which would not be a possibility unless his demented stage was part of his life, and whether a competent person can have prudential concern for the demented person he becomes, which would be out of the question unless he remained the same person throughout.

Many philosophical theories about personal identity, however, challenge the assumption that identity survives serious and permanent dementia. They argue that personal identity requires psychological continuity, so that a person who becomes seriously demented, and has no important connections of memory and personality with his former self, has ceased to exist, and the demented person he has become must be treated as a new person altogether. So the question of personal identity, in this context at least, is not a mere academic, philosophical issue or a barren semantic question. It must be faced, and resolved, in any competent theory about the rights of the demented. My own view, argued elsewhere (Dworkin 1987) is that personal identity does survive even the most serious dementia. If my claims about personal identity are wrong, and identity does not survive dementia, many of my arguments and conclusions about the rights of the demented would have to be abandoned.

Rights to Autonomy: Contemporary Autonomy

It is a familiar idea in political philosophy that adult citizens of normal competence have a right to autonomy, that is, a right to make decisions about the character of their lives for themselves. Except in very special circumstances, we reject paternalism—forcing people to act in what the government deems to be their best interest—because paternalism denies that right to autonomy. So 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. Autonomy is often at stake in medical contexts (see Buchanan and Brock 1986). A Jehovah's Witness, for example, may refuse blood transfusions necessary to save his life because he believes transfusions offensive on grounds of religious conviction. Or a patient whose life can be saved only if his legs are amputated, but who prefers

to die soon rather than to live longer in what he would regard as intolerable circumstances, is allowed to refuse the operation. American law quite generally recognizes the patient's right to autonomy in circumstances like these (see Annas and Glantz 1986).

How far do the demented have a right to autonomy? How far, that is, do they have a right to make decisions for themselves that others would deem not in their best interests? (See appendix note 1.) Should they be allowed to spend or give away their money as they wish, or to choose their doctors, or to refuse prescribed medical treatment, or to decide which of their relatives will be appointed as their guardian? How far does this depend on the importance of the decision, and the degree of their incompetence? There may, of course, be some other reason, beyond autonomy, for allowing them to do as they please. They may become so agitated, for example, if prevented from doing as they wish, that though the decision they make is not itself in their interest, we do them more harm than good by opposing them. Our present question is whether we have reason to respect their decision even when this is not so, even when we think it would be in their best interest, even all things considered, to take some decisions out of their hands.

We cannot answer that question without reflecting on the *point* or *value* of autonomy, that is, on why we should *ever* respect the decisions people make when we believe 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 think these decisions imprudent, because as a general matter each person knows what is in his own best interests better than anyone else does (see Buchanan and Brock 1986). We often think that someone has made a mistake in judging what is in his own interests, that we know better than he does what is good for him. But experience teaches us, according to this argument, that in most cases we are wrong to think this. So we do better for people's well-being, in the long run, by recognizing a general right to autonomy, which we always respect, than by reserving the right to interfere with their lives whenever we think they have made a mistake. If we accept this evidentiary account of autonomy, we will not extend the right of autonomy to decisions made by the seriously demented. For it is very implausible to assume that someone who is demented, who has lost the power to appreciate and engage in reasoning and argument, even generally knows what is in his own best interests as well as trained specialists, like doctors,

do. In some cases that assumption would be incoherent, when, for example, as is often the case, the wishes and decisions of a demented person change radically from one bout of lucidity to another.

But the evidentiary view of the point of autonomy is very far from compelling. For autonomy requires us not only to allow someone to act in what he takes to be his best interests but to allow him to act in a way he accepts is not in his interests at all. (See appendix note 2.) This is sometimes a matter of what philosophers call “weakness of the will.” Many people who smoke would prefer not to; they do not think that smoking, all things considered, is in their best interests, but they smoke anyway. If we believe, as we do, that autonomy requires allowing them to act in this way, we cannot accept that the point of autonomy is to protect an agent’s welfare. Sometimes people act against what they believe to be their own best interests for more admirable reasons. Someone who refuses medical treatment he knows he needs because he believes others, who would then have to go without, need it more, acts out of convictions we admire even if we would not act the same way. If autonomy requires us to respect such decisions, then once again autonomy is poorly explained on the view that the right to autonomy actually promotes the welfare of people making apparently imprudent decisions.

This suggests that the point of autonomy must be, at least to some large degree, independent of the claim that people know their own best interests better than other people can, and in that case it would not follow, just from the fact that a demented person will often be mistaken about his own best interests, that others are entitled to override the choices he makes. So perhaps the demented have a right to autonomy after all. The most plausible alternate view of the point of autonomy emphasizes, however, not the welfare of the choosing agent, but his *integrity*. The value of autonomy, on this view, lies in the scheme of responsibility it creates: autonomy makes each of us responsible for shaping his own life according to some coherent and distinctive sense of character, conviction, and interest. It allows us to lead our own lives rather than being led along them, so that each of us can be, to the extent a scheme of rights can make this possible, what he has made himself. This view of autonomy focuses not on individual decisions one by one, but the place of each decision in a more general program or picture of life the agent is creating and constructing, a conception of character and achievement that must be allowed its own distinctive integrity. We allow someone to choose

death over radical amputation, or even blood transfusion, if that is his informed wish, because we acknowledge his right to a life structured by his own values even when these values are not ours.

The integrity view of autonomy does not, of course, assume that normally competent people, whose autonomy we must respect, have thoroughly consistent values or always make thoroughly consistent choices. It recognizes that people often make choices that reflect weakness, indecision, caprice, or plain irrationality: that some people otherwise fanatical about their health continue to smoke, for example. So any plausible integrity-based theory of autonomy must distinguish between the general point or value of autonomy and its consequences for any particular person. Autonomy encourages and protects the capacity competent people have to direct their own lives at least generally in accordance with a scheme of value each has recognized and chosen for himself or herself. The principal value of that capacity is realized, in any particular life, only when that life does, in fact, display a general, overall integrity and authenticity. But autonomy protects and encourages the capacity by allowing people who have it themselves to choose how far and in what form they will seek to realize its value in that way, and some people will partly or largely waste it.

If we accept this integrity view of autonomy, our judgment about whether some patient has a right to autonomy will turn on the degree of that patient's capacity to direct his or her life in accordance with a recognized and coherent scheme of value, that is, capacity for integrity and authenticity. When a mildly demented person's choices are reasonably stable, reasonably continuous with the general character of his life before he became demented, and inconsistent only to the rough degree 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 one by one, systematically contradict one another, or reflect no coherent character whatever, or perhaps even if they are radically discontinuous with the values of his previous life, 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. So he has no right that his choice of a guardian, or choices about the use of his property, or about his medical treatment, be respected for reasons of autonomy. He still has the right to beneficence, that is, 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 has no right, as competent people do, himself to decide contrary to those interests.

I should emphasize that the decision whether a particular patient is sufficiently competent to have a right to autonomy, on the integrity view of that right, must be a *general* judgment about his overall capacity to seek integrity and authenticity, not a specific, task-sensitive judgment. I have in mind the following contrast. "Competence" is sometimes used in a task-specific sense to refer to the ability to grasp and manipulate information bearing on a particular problem. Competence, in that sense, always varies, sometimes greatly, even among ordinary, nondemented people; I am more competent than you at making some decisions, perhaps, but probably much less competent at others. The literature concerning surrogate decision making for the demented points out, perfectly properly, that competence, in that task-specific sense, is relative to the character and complexity of the decision in question (Buchanan and Brock 1986; see also appendix note 3). A patient who is not competent to administer his complex business affairs may nevertheless be able to grasp and appreciate information bearing on a decision whether to remain at home or to enter an institution, for example. Competence in the overall sense presupposed by the right to autonomy is a very different matter, however. It means, not the capacity to grasp particular information or solve particular problems, but the more diffuse and general capacity for integrity: the capacity to see and evaluate particular decisions in the structured context of an overall life organized around a coherent conception of character and conviction. There will, of course, be hard cases, in which we will be unable to say, at least with any confidence, whether a particular dementia patient is competent in that overall sense. But the question of autonomy requires that overall judgment, not some combination of judgments about specific task-capability. (See appendix note 4.) Patients suffering from serious dementia have plainly lost the necessary general capacity for integrity, and, as I said, have no right that *any* decision be respected just out of concern for their autonomy.

Precedent Autonomy

So neither the evidentiary view of autonomy, nor the more plausible integrity view, recommends any right to autonomy for the seriously

demented. But we have so far been considering the contemporary autonomy of a demented person; we must now consider the precedent autonomy of the person he was before. Suppose a patient is now incompetent in the general, overall sense just discussed, but that, years ago, when perfectly competent, he executed a "living will" providing that he was not to be kept alive by expensive medical treatment if he became permanently demented, or that his property was to be given to charity rather than used for his care. Does autonomy now require that such provisions be respected by those in charge of the patient if they think them against the patient's best interests? If we accept the evidentiary view of autonomy, we will think the case for respecting such precedent choices 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 will undoubtedly have changed. If we accept the integrity view, on the other hand, we will be drawn to the view that precedent autonomy must be respected, because it seems essential to someone's control of his whole life that he be able to dictate what will happen to him when he becomes incompetent. A competent person, making a living will providing for his treatment if he becomes demented, is making the kind of judgment that autonomy, on the integrity view, respects, a judgment about the overall shape or character of the kind of life he wants to have led.

But it might now be objected that the right to autonomy is *necessarily* contemporary: that it is only a right that someone's *present* decision be respected. Certainly that is the normal force of recognizing autonomy. Suppose that a Jehovah's Witness, whose religious convictions so require, has signed a formal document stipulating that he is not to receive blood transfusions even if he, out of weakness of will, requests them when he will 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 that plea to honor his former, formal request. We can interpret that example in two different ways, however, and the difference becomes important when we consider whether autonomy requires enforcing prior decisions about one's treatment when demented. We can say, first, that the later plea countermanded the original decision because the plea expressed a contemporary desire. On that view, it is right to defer to past decisions only when we have reason to think that the agent still wishes what he chose

then; we treat the past decision, that is, as evidence of present wish, and disregard that decision when we have reason to think it is not, in fact, good evidence of that. On this view precedent autonomy is an illusion: we attend to past decisions only as rebuttable evidence of contemporary preference or choice. Second, we can say that the later plea countermands the original decision because the later plea counts as a fresh exercise of autonomy, that if we disregarded it we would be treating the person who pleads as no longer in charge of his own life. The difference between these two accounts of the force of autonomy is crucial when the conditions of autonomy no longer hold when someone changes his mind. Suppose that the same accident that made a transfusion medically necessary for the Jehovah's Witness also deranged him and, 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 view of autonomy is right? Suppose we were confident that the Jehovah's Witness, if he receives the transfusion and lives, will become competent again, and will then be appalled at having had a treatment he believes was much worse for him than dying. In those circumstances, I believe, we would be violating his autonomy by nevertheless giving him the transfusion while he is deranged. That argues for the second view of autonomy, the view that endorses precedent autonomy. The deranged Jehovah's Witness does *not* object to the transfusion: he wants it. This is not, that is, like the case in which someone who objects to a treatment is asleep or unconscious when he needs it; in that case we can say (using a dispositional sense of objecting) that he continues to object then. If we withhold the transfusion from the deranged Jehovah's Witness, we withhold it in spite of the fact that he wants it then. We are relying on the fact that he does not have the capacity necessary for his wants to count in countermanding what he wanted when he was competent, and that means we are relying on the second view of autonomy's point. Someone might object that we are actually relying, not on any lack of capacity, but on the assumed fact that the Jehovah's Witness will regret the transfusion, if he receives it, when he becomes competent again. But we would take a different view if the Jehovah's Witness had not become temporarily deranged. Suppose he pleads for the transfusion at the moment when he needs it, not because he is temporarily deranged, but just because he finds he wants to live at that moment,

though we are confident that he will change his mind and be appalled at his decision tomorrow. If we would accede to his request for the transfusion when he wants it (as I believe we should), that shows that we are not relying, in the case when he has become deranged, just on the fact that we predict he will have a different opinion when he recovers his senses. That fact seems important, in that case, only because it confirms that he had not changed his mind when he was still competent to do so.

Our argument, then, supports the idea 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 do not represent, and even if they contradict, the desires he has when we respect them, provided he did not change his mind while he was still in charge of his own life. If we refused to accept precedent autonomy, and instead insisted that past decisions made when competent will not be enforced unless they represent the present wishes of the incompetent patient, we would be violating the point of autonomy on the integrity view. For competent people, concerned to give their lives the structure integrity demands, will naturally be concerned about how they are treated when demented. Someone anxious to insure that his life is not then prolonged by medical treatment is anxious exactly because he thinks the character of his whole life would be compromised if that life were prolonged in that way. This argument has austere consequences, however. Many would be outraged by the prospect of denying an incompetent patient life-prolonging care he pleads for, of allowing someone to die who very much wants to live, just because, years earlier, he signed a document requiring this. I have been arguing that his right to autonomy—the right of the person he has become and remains—unambiguously requires that his pleas now be denied; he is not like the imagined Jehovah's Witness who changed his mind when he knew he was dying. (See appendix note 5.) We may be unable to deny him. We may think that people who refuse pleas for life for any reason are inhumane. Or we may have other good reasons for treating him as he now demands. But if so these are reasons that violate, rather than enforce, his autonomy.

I end this discussion of autonomy with one final distinction. We must distinguish the precedent autonomy we have now recognized from other ideas with which it may easily be confused. Commentators and judges have said, for example, that crucial decisions affecting the

care of dementia patients should reflect the decisions the patient probably would have made himself if he were competent.¹ (So a patient's family succeeded in persuading a judge to terminate his care by arguing that he had been, when competent, a vital person who very much enjoyed physical activity of which he was no longer capable, which suggests that he would not wish to continue living were he competent to make that choice.)² Speculation about what a demented person would have preferred under assumed conditions of competence may be relevant to determining what is in that person's best interests, and so what he or she is entitled to have under a right to beneficence. (See appendix note 6.) But any appeal to a right to precedent autonomy requires evidence of an actual past decision contemplating the circumstances the patient is now in. It is not enough to argue that a particular conviction (for instance, the desire not to have one's life prolonged) would be more consistent with the patient's former habits and patterns of life than any contrary conviction. The point of autonomy, on the integrity view, is to allow an agent to construct his own life and character according to his own lights, not to allow others to make, for him, a life they think most consistent in ideal or character. So for the great majority of dementia victims who have made no such actual decision the right to precedent autonomy plays no part in any contemporary decision made by others on their behalf.

Appendix Notes

1. 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 count the fact that his autonomy is to some degree compromised, considered in itself, as against his interests.

¹ See, e.g., *In Re Quinlan*, 355 A.2d 647, cert. den. 429 U.S. 922 (N.J., 1976).

² See *In Re Spring*, 405 N.E.2d 115 (Mass. 1980). See the discussion of this decision, and of *In Re Quinlan*, supra, and *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 755 (1977), in the Buchanan and Brock article in this volume. That report identifies the confusion noticed in the text.

2. 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 be. See, e.g., Amartya, S. 1977. Rational Fools: A Critique of the Behavioral Foundations of Economic Theory. *Philosophy and Public Affairs* 6 (4).

3. Questions of task-sensitive competence are plainly relevant to the issues considered in the Buchanan and Brock article. But when the argument against surrogate decision making relies on the autonomy of the demented person affected by these decisions, the overall, nontask-sensitive sense of competence is also relevant.

4. Problems are presented, for this judgment 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 give structure to a continuing life.

5. I am assuming, in this contrast, that at least some cases of what the philosophers call weakness of will—failing to abide by settled convictions in a moment of great temptation—are nevertheless exercises of autonomy. It would be, I think, a serious mistake to conflate two very different situations: when someone has the general capacity to bend his life to his convictions, and does not exercise this, and when he has become demented and so lost the capacity altogether.

6. Since such speculation has only evidentiary value, it may be somewhat misleading to treat "substituted judgment" and "best interests" as two different, independent tests of what may or should be done to or for a demented person. See also Annas and Glantz 1986.

References

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