

Dementia, identity and the role of friends

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Abstract Ronald Dworkin (1993) introduced the example of Margo, who was so severely demented that she could not recognise any family or friends, and could not remember anything of her life. At the same time, however, she seemed full of childish delight. Dworkin also imagines that, before her dementia, Margo signed an advance refusal of life-saving treatment. Now severely demented, she develops pneumonia, easy to treat, but lethal if untreated. Dworkin argues that the advance refusal ought to be heeded and Margo be allowed to die of that pneumonia, on the basis that the prior refusal expresses her true wishes (her ‘critical interests’). In this paper I want to challenge Dworkin’s understanding of identity and his conclusion about advance refusals, and I develop my argument in two directions. First, I argue that the demented Margo is not some ‘lesser’ version of the ‘true’ Margo, but instead that the present Margo’s wishes should take precedence over those of the past Margo, on the grounds that all of us are entitled to change our minds. Second, I argue for a stronger role for friends and family members in sustaining the demented Margo’s identity through her years of decline. Based on this, I argue for a presumption against the advance refusal, but I allow that in extreme cases (which I describe), a friend might have the authority to demand that it be heeded.

Keywords Dementia · Personal identity · Friendship · Advance directives

Dementia, identity and the role of friends

In his classic 1993 book *Life’s Dominion*, Ronald Dworkin discusses the example of Margo,¹ who was so severely demented that she could not recognise any family or friends, could not remember anything of her life, and indeed could not remember what she had for breakfast. She seemed to live in an eternal present. Importantly, however, she seemed very happy, full of childish delights. Dworkin is interested in the question of who Margo is, and what relation she has with her earlier life.

He focuses the ethical issue by imagining Margo to have written an advance refusal of life-saving treatment. For the sake of clarity, let me add some details to Dworkin’s example: Margo first learns the diagnosis at the age of 50, when she is still competent to make legally binding decisions, but also when she still has a job, manages a house, and has rich relationships with family members, friends, and colleagues. She draws up the advance refusal, saying essentially that if, once severely demented, she develops a life-threatening disease, she hereby requests that no life-saving treatment (e.g. anti-biotics) be administered to her, even when such treatment is effective, non-burdensome, and cheap. 10 years later, Margo is 60 years old and the worst has come to pass: she is now severely demented, and in addition has recently developed a case of life-threatening pneumonia. Dworkin argues that the doctor should withhold the treatment and allow Margo to die on the basis of her advance refusal. The ‘real’ Margo expressed her wishes in the advance refusal, and it is those wishes which must prevail, regardless of how enjoyable life appears to be to the present, demented Margo.

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¹ According to Dworkin, the original example came from Firlík 1991.

The problem of advance directives and advance refusals (or ‘living wills’) is still in active discussion among philosophers, legal theorists and clinicians.² The legal status of advance refusals varies, and is often ambiguous, but for my purposes I will be focusing more on the ethical and metaphysical issues. In this paper I want to argue that Dworkin’s account of personal identity, which grounds the above conclusion in favour of honouring the advance refusal, is incomplete. I want to suggest a way of supplementing that account by describing a new component of identity, one that assumes greater prominence precisely in cases of advanced dementia. Using an idea of Hilde Lindemann’s, I will argue that our identity in normal competent adulthood is partly constituted by our intimate relationships with friends and family, and that these friends and family members can ‘hold’ something of the identity of the demented patient even after the loss of experiential memory. This alternative understanding of identity then leads to different conclusions about what to do in the advance refusal scenario.

The problem of identity

The classic problem of identity, familiar from John Locke, takes two objects: B1 at time T1 and B2 at time T2, and asks whether, and according to what criteria, B2 is numerically the same as B1 (even if qualitatively different). The most obvious answer has to do with the single path traced through space and time without splitting or merging. This table here and now is the same table as the one here yesterday. This criterion comes under strain in certain cases: my pen worked properly yesterday, I can trace a single spatio-temporal path through to this pen in my hand right now, but this pen does not work, is it still the same pen? In one sense it is, in another it isn’t. Further strain appears with the cases of living beings, which may grow up or grow old. Even if this tree had quite different physical properties from the sapling planted by my grandmother, it still makes sense to speak of *this* tree having been planted *then* by my grandmother. However, it also makes sense to speak of the sapling turning into this tree.

Humans are a special case of living beings because they not only trace a unique physical path through space and time despite qualitative changes, but mainly because of experiential memory: roughly, B2 is the same person as B1 if she remembers *being* B1. This psychological connectedness can then be extended and deepened beyond experiential memory by the continuing retrospective construction of one’s life, where ‘life’ is to be understood not biologically but

narratively. B2 now is the same person as B1 then in virtue of sharing a single story: the story that B2 tells about how she got to where she is now, and about the planned trajectory into the future, undergirded by a more-or-less stable character, and loosely guided by a set of ideals, hopes, fears, guilt etc.³

In normal adults, the bodily and the psychological criteria work in concert, and there is rarely a problem in re-identifying an individual as the same: so many of our social, moral and legal relationships presuppose this reliable capacity. There may be some difficulties with people who cannot understand why they made a decision many years ago (“what got into me?” “Why on earth did I marry him?”). There will be other difficulties in assigning moral and legal responsibility for things I did when heavily drunk, so that it is not clear how much my actions were *mine* at the time, especially when I can only remember them vaguely now. But these instances generate their distinctive poignancy and frustration precisely because they are exceptional among so many social practices presupposing stable identity (and self-identity) attributions.

Sometimes character does change, but usually this is a slow process over years and decades. At 20, I vote Labour, but at 40, I vote Conservative. But between 40 and 41, my political views remain relatively settled, as do my greed, my sense of caution and my wit. Exceptionally the change can be short-term and drastic, as when a soldier is quickly brutalised by war, and upon his return his wife declares “he’s not the man I married.” Clearly he is the same man in terms of his body and of his experiential memory, and he would certainly be held to the mortgage contract he freely signed before going off to war. It is because he fulfils so many of the criteria of identity that generates the tragic expectation that he will be the same in character as what the wife remembers.

It might be said that the experiential memory criterion is more important than the body criterion. John Locke offered the example of the prince and the cobbler swapping their minds;⁴ the point of the thought experiment is that we would be inclined to say that the particular *person* went where the *mind* (and the experiential memory) went, even to another body. Ultimately we could get used to the prince in the cobbler’s body, thought Locke.

Dworkin could be described as sharing this priority of the psychological over the physical in the case of the severely demented patient. The 60-year-old Margo is instantly

² See, for example (Dresser 2014; Menzel and Steinbock 2013; Muramoto 2011); for a discussion explicitly on Dworkin, see Dresser (1995).

³ There is of course a risk of other-deception and self-deception, more or less deliberate or accidental, throughout the story-telling. A person of integrity can be described as a person for whom the story that *she* tells mostly matches up with the story that *others* tell about her life.

⁴ The starting point for the contemporary discussion of personal identity is Parfit (1984), who explored and hugely developed Locke’s example.

recognisable in possessing the same face and same body as the 50-year-old I remember meeting. She may even have retained certain character and personality traits. So it comes as a profound shock for me, visiting Margo for the first time in 10 years, to learn that she has lost all experiential memory, both of me, and of the role I spent in her life. Indeed, when I show her a picture of the two of us from 10 years ago, she does not seem to recognise either person in the picture.

Some people are so traumatised by the patient's loss of experiential memory that paradoxically they seek some modest solace in the language of death: "the real Margo died a few years ago," or "this is only an empty shell." (The same sorts of thing can and have been said about patients in a coma.) De Grazia (1999) calls this the 'someone else problem'—this person in front of us *looks* so much like Margo and yet it's not, it's someone else. When it comes to the advance refusal, this conception quickly solves the problem, since the advance refusal does not concern this someone else, and therefore can be ignored entirely. We would treat this demented person as if she were any other person with similar cognitive impairments, and as if she had had them since birth. With such a person we would quickly treat the pneumonia—unless the situation was complicated by the patient's prolonged distress and/or serious comorbidities such as cancer or stroke. To keep things simple, however, I will concentrate on Margo, who is cheerful and physiologically healthy.

As a distressed personal response to another person's dementia, the temptation to see her as "someone else" is understandable, but it is hard to sustain in reality. Most importantly, we—both visitors and nursing staff—call the patient by her name, the same name she has always had. If the 'real' Margo was dead, then there would be nothing in principle wrong with the nursing home staff renaming the patient, but of course such a move would be profoundly cruel and disrespectful; moreover it would be cruel and disrespectful *to Margo*, to this patient here in front of us, the same person as the younger version in those photographs around her room. Similarly, if the 'real' Margo were dead, and her body usurped, it would not make sense for family members to visit this usurper, nor for them to bring photographs and to talk to Margo about the people in them.

Dworkin's solution

For the purposes of this paper I'm going to ignore the "someone else problem", since I want to focus on a different problem. We still have Dworkin's dilemma: whether to withhold life-saving treatment from the severely demented Margo-at-60, despite the latter's evident cheerfulness (i.e. despite our inference that she wishes to continue living), on the basis of the advance refusal Margo wrote 10 years

previously. To solve this problem, Dworkin relies on a weaker form of the distinction between the 'more real' and the 'less real' Margo in order to determine whose wishes should be authoritative.

For Dworkin, every human being has 'critical' and 'experiential' interests. Experiential interests have to do with present pleasure; to the extent that we know (or it is known) what gives us pleasure now, then we have an interest in receiving such pleasure. Margo-at-60 has plenty of experiential interests, as do we all. Critical interests, on the other hand, have to do with the meaningfulness of an activity or relationship in a person's life; with the long-term projects and commitments—some chosen, some unchosen—that guide the bigger decisions in one's life. Dworkin offers the example of his children. Even if his children would not satisfy his experiential interests right at a given moment, Dworkin considers that their existence and his relationship with them is an important source of meaning in his life. It is in Dworkin's critical interest to cultivate and sustain that relationship even when he is not spontaneously inclined to do so. We might call this relationship to his children part of what is *essential* to who Dworkin is. If he ever ceases to care at all about his children (if he is inclined over the longer-term to see them as offering him no further joy or meaning e.g. because of what they have become or done), and they drift away, this might not affect his experiential interests ("I don't miss the little brats at all!"), but it would amount to a loss in Dworkin's life.⁵

According to Dworkin, Margo-at-50, upon receiving the dementia diagnosis, reasonably feared the harm to her long-term critical interests that would come with the imminent loss of experiential memory and the accompanying inability to recognise her friends and family; insofar as the critical interests are essential to that person, Margo believed she could not remain Margo in the full sense while suffering such harm to her critical interests. The Margo-at-60 that remained after such a harm would still be Margo, and would still have plenty of experiential interests—and Margo-at-50 knows this—but it would be a highly attenuated version of the essential Margo that transcends time. If Margo-at-50 reflects seriously on the issue and then writes the advance refusal, says Dworkin, this has to be taken as a sincere

⁵ There is an equivocation here, however. Let's say that Dworkin at 30 loves his children and values his relationship with them. He says to himself "if I ever lose this relationship, that will be a loss." 20 years pass, let's say the children have descended into vice, crime and corruption, and Dworkin loses spontaneous interest in them, especially as his own career absorbs him more and more. Now the 30-year-old Dworkin would describe this as a loss. But the 50-year-old Dworkin might declare that his critical interests have simply *changed*; and he doesn't feel as if he has lost anything *given* what his children have become and *given* the many other critical interests that he has developed over the 20 years.

expression of her critical interests, and thereby retain authority over changing experiential interests when deciding what should happen to Margo once she is demented at 60. In other words, concludes Dworkin, the life-saving treatment should be withheld in accordance with the authoritative wishes of the earlier, ‘real’ Margo, and the attenuated Margo should be allowed to die.

Dworkin’s theoretical set-up is fine as far as it goes, but he neglects two important aspects of the situation, both of which would lead—I will argue—to a robust presumption that the advance refusal should be *ignored* and Margo-at-60’s life saved by administering the antibiotics.

The first aspect: the doctor’s moral reluctance

The first aspect has to do with a deep reluctance to apply Dworkin’s conclusion, no matter how much one might intellectually agree with it. And this reluctance is ethical, it is not merely psychological. Assume I am the physician attending Margo. Here in front of me is the demented Margo with her childish delights, but right now she is suffering from pneumonia—something that is straightforward, non-burdensome and cheap for me to treat. I am acutely aware of my power to restore her to physical health. However, in my hand I have Margo’s advance refusal, with its clear instructions for exactly this kind of situation, and the instructions call for me to let her die (perhaps with some sedation). Here’s the point: I don’t think I would be able to let her die. This is not only a point about doctors being trained to help people and save lives as far as possible. It is also a point about the person in front of me, who is so full of life, so cheerful, and so easy to save. Whereas the original author of the advance directive is, quite simply, not in front of me.

I stress again that my reluctance would be ethical and not psychological, and therefore it is a reluctance worth taking seriously. Doctors have to do (and they know they have to do) plenty of things that they might be psychologically reluctant to do. A doctor with vertigo might be reluctant to go out on a high balcony to persuade a suicidal patient to come back inside, but they go out on the balcony anyway. A medical student may have plenty of psychological squeamishness about the blood and the guts and the excrement, but she knows she has to overcome that to do her job. In contrast, an ethical reluctance has to do with a concern about doing a serious ethical wrong. In the case of the demented but healthy and cheerful Margo, withholding effective treatment comes too close to, at best abandonment, at worst killing.

It will be objected that I am confusing ethics with something like a “personal morality,” and that personal morality, just like psychological reluctance, should be ignored in order

to make the ethically correct decision in the situation.⁶ I want to park this objection, and return to it in the concluding section of the paper. For the moment let me summarise my response thus: I am taking personal morality seriously in the sense that I would take a pacifist’s conscientious objection to a just war seriously. Such an expression of morality may be ‘personal’ but it is not *merely* personal; for the pacifist, it has all the force of a discoverable objective ethical principle, and is entirely distinct from psychological aversion.

The second aspect: the possibility of changing one’s mind

Importantly, this does not commit me to the “someone else problem.” Rather, I am still taking Margo-at-50 and Margo-at-60 to be the same person, but I want to re-conceive the situation as a matter of Margo having *changed her mind* about living with dementia, and in that sense her past wishes have lost their authority.⁷ Everyone changes their mind, about all sorts of things, and everyone has the right to change their mind: it is only the most recent version of a last will that is legally valid, for example. More generally, there is a presumption in most social interaction that we should heed the other person’s most recent wishes over their earlier ones. It might be interesting to learn which political party a person voted for in the previous elections, but what matters to pollsters, to parties, and to friends and family members (perhaps to their consternation), is the party they intend to vote for in the upcoming election.⁸

Implicit in Margo’s cheerfulness is the rejection of the advance refusal, as if to say: “I know I dreaded dementia, I know I asked to be allowed to die, but right now life is actually not so bad as I thought it would be.” Of course part of the very problem of dementia is that the patient cannot even articulate the self-reflective thought that “life is not so bad”, but I would argue that a doctor’s if-in-doubt response should always be the preservation of life. We would certainly expect such an if-in-doubt response from a doctor when she deals with a patient who has the same cognitive impairments as Margo, but from birth. This is more than the

⁶ This objection was forcefully articulated by an anonymous reviewer.

⁷ Indeed, I might also be accused of keeping Margo’s *body* alive against the wishes of Margo’s *mind*, simply out of misguided technological zeal. This accusation is sometimes levelled against doctors in the event of a comatose patient. However, it is important for my discussion that I (as the physician) am struck by Margo’s entire person, she is much more than a living body.

⁸ Importantly, I am not assuming that, in changing your mind as you age, you are necessarily *improving* your opinion, or achieving either greater wisdom or authenticity. Many become more foolish with age! The greater authority of the later opinion is only based on the time-ordering.

familiar sanctity-of-life argument; for I am arguing for the sanctity of *Margo's* life, and her narrative rather than merely biological life.

It could be argued that I (in my role as doctor) am allowing myself to be swayed illegitimately by my affection for the Margo in front of me, whereas I should decide the matter more 'objectively', free from the psychological distortion produced by any spontaneous affection (or indeed by any aversion). I should imagine *both* Margo-at-50 and Margo-at-60 standing before me, making their respective demands, and I should decide the matter with reference to something like the 'real' Margo, or to Margo's critical interests. In response, all I can do is repeat that Margo-at-50 is a figure of the past, she cannot come before me; at the same time, my affection for Margo-at-60 *is* relevant to the decision of whether to allow *her* to die. It is not clear how I could honestly cite Margo-at-50's wishes as a justification—to Margo-at-60 *herself*, the cheerful person here in front of me—for allowing *her*, Margo-at-60, to die. For all of her behaviour suggests that she does not want to die. To be honest I don't even know what Margo's critical interests are any more, but I am very confident that I know what her experiential interests are, and so yes, I would grant priority to the latter.

Dworkin might well respond as follows: the principle of revisability (the right to change one's mind) only applies insofar as the individual remains competent throughout the change, precisely so that she can give the *reasons* for changing her mind, and reasons for her new position. In the case of Margo-at-60, he would say, she has lost the ability to change her mind for reasons, and this reduces the authority of her inferred wishes (at 60) compared with her earlier, competent, *reasoned* wishes. It amounts to giving priority to her experiential interests over her critical interests, the latter as reliably expressed in the advanced refusal.

In response, I would argue that philosophers and political theorists place too much emphasis on reasons as the structural support for autonomy, and are too quick to reject a person's decision as whimsical or capricious if it is not or cannot be fully justified by reasons. Many of the most important decisions one can make in life cannot be fully and conclusively justified by reasons, and attempts to justify them will inevitably smack of post-hoc rationalisation. When I tell people I voted for Labour, I can give reasons why I did so. But such first-order reasons will beg further second-order reasons about the salience with which I considered the first-order reasons, and about my second-order reasons for rejecting other putatively good reasons for voting Conservative. Throughout the process, the 'reasons' I am giving are not justificatory, but descriptive: they reveal further levels of detail about my deliberations. At a certain point, however, I can only say "Labour seems to care about the sort of things that I care about." Then, as I age, and the structure of my cares change, sometimes unpredictably, I might find that I

am less attracted to the Labour manifesto than I was before. Can I give an authoritative reason for my cares changing, a reason that does *more* than provide further biographical details with speculations about causal influence (e.g. as my career advances and I make more money, I come to resent Labour's priority of higher taxes)? I suggest not. All we are left with, over longer time periods, is the brute fact that I voted Labour at 20 and then I voted Conservative at 40. Neither was the 'correct' vote (in the sense of corresponding to an external truth), nor was either of them an 'authentic' vote (in the sense of corresponding with a permanent internal truth of me). However, when you talk to me, at age 40, then my past voter preferences are no longer relevant. I have changed my mind. Maybe you will not like the reasons I give you for changing my mind, maybe you will call be ignorant, and we will have a political discussion, which *might* end up with your persuading me to change my mind again. So be it. But there can be no guarantee that you will succeed in your efforts, and you will not automatically be able to write me off as ignorant and irrational if you fail.

I realise that changing my mind about my political allegiance is still moving from one competent stage to another competent stage in my life, rather than moving from competence to incompetence, as in the case of Margo. But I think that the non-centrality of reasons in ordinary mind-changing allows me to challenge Dworkin's priority of critical over experiential interests when the two pull in different directions, as in the case of Margo. With Dworkin, I accept the continuity of Margo's life, but I reject his view that her supra-temporal, real self was only evident at the age of 50, when she signed the refusal. I would say that her loss of competence amounted to a change of mind like any other.

The nature and role of reasons is clearly too big a discussion for this article, and there are enough ways of rejecting the above line of thought and thereby to put an end to my argument. But for those who can accept the above as sufficiently plausible, I think they lead to some interesting conclusions. The upshot for Margo is that I want to take her 60-year-old version as assuming *greater* authority over her 50-year-old version, and I want to take her as having legitimately changed her mind rather than as having lost her mind.

The intimacy criterion

Even if I have rejected Dworkin's argument for critical interests as grounding the respect for Margo-at-50's advance refusal, I acknowledge that there is still a tension in what remains, and this tension is keenly felt by every friend and relative who comes to visit Margo-at-60, despite the fact that Margo seems to be enjoying life—indeed, it could be said that the tension arises precisely because Margo does seem to enjoy her life, without being aware of what she has lost.

This tension could be put in terms of a paradox of pity: the friend will probably feel deep pity for Margo, and yet Margo does not pity herself, and would not understand the friend's response of pity. I want to suggest a different response that friends can show Margo, one that would be more appropriate than pity.

Recall the two traditional criteria of personal identity, the bodily and the psychological, with a special emphasis on experiential memory.⁹ I want to propose a third criterion, which I will call the 'intimacy criterion'. In normal situations, B1 and B2 are the same person across time, not only if they share a single body through that time, not only if they have the right relations of psychological connectedness across that time (including the fact that B2 can remember being B1), but also because they are in the same on-going intimate relationships with the same friends and family members, colleagues, fellow enthusiasts, co-religionists across that time. For simplicity I will call all these people "friends". Each of us lives in a nexus of different, overlapping, and shifting relationships with friends. Indeed, not only are one's intimate friendships a criterion of identity (is B2 the same as B1?), but, more importantly for my purposes, they are also partly *constitutive* of identity.¹⁰

I take my cue partly from Dworkin's example of the critical interest he has in the relationship with his children. The idea should be familiar. Many times I do not quite know what to think about an issue until I have talked it through with a trusted friend, a friend who has known me for a while, and who can give me good advice precisely because she knows the bigger picture of my life. Sometimes a friend can know me better than I know myself, and criticise me precisely for deceiving myself about what I think I want or need.¹¹ Sometimes a friend can criticise me with greater authority—for being ignoble or stingy, say—than can a stranger, even a stranger with expertise in psychology or in writing biographies. Sometimes a friend can "bring out the best in me." This is not merely a point about my friend's *knowledge* of me; it is also a point about shared *being* in the world. When my friend suffers, then I suffer—indeed I may

be more vulnerable to certain kinds of harm befalling my friend than I am to the same harm befalling me (particularly in the case of my children). I and my friend share many interests, and part of our enjoyment of certain activities is that we partake in them together, discuss them together, and evaluate each other's performance in the activities in light of our shared understanding of their quality. This metaphysical interposition is nicely summarised by the phrase: "when my friend died, a part of me died with her."¹²

I also take a cue from two other philosophers. The first is Gedge (2004), who emphasises the imagined dialogue between a demented patient and her friend, and uses this not only to criticise the alleged discontinuity of selves between the pre-demented and the demented patient, but also the 'bridging' role of 'intimate proxy decision-makers'. In what follows I want to develop this idea of 'bridging'. The second is Hilde Lindemann's (2009) example of 'holding' a demented patient. Lindemann argues that it is important for friends to visit the severely demented patient in order to conserve their humanity, precisely because the patient herself is no longer concerned with her own humanity. The friend can help to prevent the patient from slipping away from the community entirely into a solipsist eternal present. Even if the patient does not notice the friend's visit, does not recognise the friend, and does not understand what the friend is doing, the friend is holding the patient 'above water', as it were, for as long as possible. While the demented patient's physical needs are being met by the nursing home staff, there is a risk of insufficient attention to the patient's needs beyond their physical needs, and this is why friends' visits were so important.¹³

Now, while Lindemann is interested in holding the patient's *humanity*, I think her insight can also be adapted to the possibility of holding the patient's *identity*. What I have in mind is the way that, between normal competent friends, one can hold the other's identity in order to ward off depression and despair. The depressed individual might be tempted to retreat from the world, and the friend does more than simply cheer and motivate her; she also holds her in the world and in her roles and relationships, helps her carry

⁹ Matthews (2006) lays the emphasis on the character criterion as a way of preserving identity in severely demented patients. I am pessimistic about his attempt, however, because character traits remain too *general* to individuate. If Smith is irascible before and after becoming demented, that does not help me identify the demented patient as *my friend Smith*, even if it adds to the uncanny first impression generated by his stable physical appearance.

¹⁰ In what follows I will be assuming that the category of 'friend' can be defined with enough precision to be normative; that is, I will be speculating on what a good friend should do. I am rejecting the thought that the concept of friendship is too diverse to allow for any plausible normativity of behaviour.

¹¹ A starting point in the debate around 'relational autonomy', not only in feminist thought but elsewhere, is Mackenzie (2000).

¹² In the case of family members, there is the added biological—and I would argue *metaphysical*—quality of sharing flesh and blood. This is important in the sense that my sister can never stop being my sister. This raises interesting questions of identity which I cannot pursue here, and so I shall continue with the broad category of 'friend' as including blood relatives.

¹³ Love is sometimes described as 'illuminating' the beloved, to the point where third parties come to see the individual as valuable and lovable, even despite the objective degradation of the individual. In this conception, love does not merely confer a psychological boost, it is transformative. On this, see Gaita's (2000, p. 18–22) striking description of the nun working at a psychiatric hospital.

out her duties and commitments, reminds her of what she believes in, maintains her as the specific individual she is.

Let us return to Margo, and let us imagine one of her oldest friends, named Ruth. They met at university, and remained friends through the developments in their respective professional and family lives. Now Margo is aged 60 and severely demented, living in a nursing home, and the 60-year-old Ruth visits her regularly.¹⁴ Margo does not recognise Ruth, does not distinguish her from the nursing home staff, does not seem to understand much of what Ruth says, does not recognise the framed pictures of the youthful Ruth and Margo that Ruth has placed around the room. If Ruth decided to stop visiting, then Margo would probably not notice at all. (I am assuming that Margo does not even have fleeting moments of recognition or lucidity.) In short, it would seem there is no longer a friendship there, and that Ruth is carrying out a very one-sided conversation. But there is more to it than meets the eye, I suggest.

Ter Meulen and Wright (2012) are on the right lines when they suggest that Ruth has a special duty of *solidarity* to visit the demented Margo, a duty grounded in their prior friendship. This sort of solidarity is to be distinguished from the general solidarity of the detached healthcare worker with no prior relationship to the particular patient. This is a good point, but I think it can go further. First, what Ruth owes is more than solidarity, she owes friendship; second, what she owes is not on the basis of *past* friendship, but of *present and past* friendship; she does not act “for old times’ sake,” let alone out of guilt or charity, but in direct response to the present needs of her friend here and now. The present response is the natural continuation of the past. Of course the relationship has changed radically and tragically, and the conversation is now very much one-sided. But it makes perfect sense for Ruth to explain to a third party that she has to visit a “friend,” rather than an ex-friend.

On the one hand we can speak of Margo remaining Margo despite the catastrophic changes in her experiential memory; on the other we can speak of the *friendship* remaining a single friendship across time despite huge changes in the nature of that friendship. It is wrong to see the friendship as essentially constituted by the symmetrical conversation and shared activities that characterise friendships at their beginning; with the implication that when the conversation and activities end the friendship must also come to an end. If Ruth were to cease visiting Margo now, Margo would probably not experience it as a betrayal. But it would still be a betrayal; and a betrayal of Margo, a betrayal of their

present friendship. In the same way that a bad ending can ruin a good story, in the same way that adversity can reveal an individual’s true mettle, such a failure would undermine the entire friendship, revealing that Ruth was never serious about the friendship *all along*.

Margo remains ‘in’ the friendship even if she would not recognise it as such, even if she cannot contribute or engage in it, even if she is bored or confused by this strange ‘Ruth’ person in front of her, and even if she forgets about Ruth’s visit soon after Ruth leaves. It would be wrong to ask ‘what good’ Ruth’s visits do, for the visits are not about an empirically testable achievement. A well-meaning nurse might reassure Ruth that it is not necessary to come so often, since Margo would not notice the absence. But Ruth does not *choose* to come—she discovers that she “has to” come, for the sake of Margo, for the sake of their friendship. It is clear that I understand the concept of friendship as something transcending visible friendly behaviour, friendly interaction and friendly conversation. But I am relying on the guiding intuition that Ruth would still describe Margo as “my friend.”

If this sounds far-fetched to some, allow me a brief aside on philosophical method: I want to start by taking seriously what people do, what they are inclined to say, how they are inclined to think. And the perhaps remarkable thing about friends of dementia patients is that some of them do visit, do engage in (one-sided) conversation, do bring photos to decorate the room. It would be very difficult to call such behaviour irrational, or self-deceptive, or merely therapeutic, or to accuse them of indulging some sort of fantasy. And the difficulty has nothing to do with the difficulty of informing someone of a hard truth: for Ruth knows full well that Margo is demented.¹⁵

To conclude this section: friendships are fragile, and need work even when everything is going well. Once Margo has become demented, maintaining the friendship is up to Ruth alone, as guardian of the friendship, and thereby, as the guardian of what is left of Margo’s identity. Of course it is arduous and dispiriting to keep the ‘conversation’ going, and it is always tempting to collapse into blunt pity. But here we can speak of Ruth having a clear moral obligation to continue visiting, and to continue maintaining the friendship, and to continue holding Margo above water for as long as possible.

¹⁴ I am not assuming that Ruth has accepted a formal role in this respect, e.g. a Durable Power of Attorney in Health Care (DPAHC). That raises separate questions that would complicate my discussion too much.

¹⁵ In a similar vein, imagine a widower going to visit the grave of his wife, and talking to ‘her’. My inclination is to take such behaviour seriously, without seeing the widower as irrational or superstitious or hallucinating or self-indulgent. Of course he knows that his wife is dead and that her body is decaying under the soil: and yet I would be inclined to say that the relationship with the wife remains in some form after her death.

The friend and the advance refusal

Let us return to the doctor's dilemma of whether to withhold life-saving treatment from the demented Margo on the basis of the advance refusal she signed 10 years ago. Recall that Dworkin argues in favour of heeding the advance refusal on the grounds that it was made by Margo at the time when she could express her critical interests, the interests that were more essential to her identity than her present experiential interests. In contrast, I imagined myself as a doctor being unable—ethically unable—to heed the advance refusal because I was struck by how much Margo seemed to be enjoying her life, and by how easy it would be to save her. The major part of that has to do with my role of doctor, and with the fact I have no prior relationship with Margo: as such she strikes me in the same way as a patient who has had the same cognitive impairments since birth.

We now have a third party present at the bedside, as it were: Ruth. Given my understanding of Ruth's role in 'holding' Margo's identity, does anything follow for the sort of advice she might give the doctor about heeding or ignoring the advance refusal? My first inclination would be to say that Ruth's role commits her to supporting Margo's continuing life and therefore ignoring the refusal. I say "commits her" in the sense that I think it would be hard to square her commitment to the *present* Margo, to her friend, with a judgement that comes too close to an abandonment of that friend. And if I were the doctor, that is what I would expect of an old friend—one who had corroborated her status as old friend by continuing to visit Margo despite her severe dementia.

However, I can also imagine an extreme case where Ruth would advise heeding the advance refusal. But it has to be an extreme case, one that involves Ruth *demanding* that I (as the doctor) heed the refusal, that is, she has to go far beyond mere advice. And Ruth's demand has to be appropriately upsetting for Ruth herself; there cannot be any suggestion of Ruth seeking relief or expediency. I can imagine a situation where Ruth visits Margo in the nursing home, over a long enough period, and eventually concludes that Margo no longer wishes to live. Of course I have described Margo as severely demented, and therefore as unable to express her wishes. But perhaps there are some fleeting moments of lucidity in which only an attentive old friend could confidently recognise an autonomous wish, a wish that fits with what the friend already knows and understands about the patient and her life. The important point is that Ruth, as an old friend, would have a special moral authority in demanding that the refusal be heeded. And such a demand would have to be the culmination of a process of interaction and discovery with the demented Margo. If Ruth was anything less than certain (and if there were any doubt about the authenticity of the advance refusal), then Margo ought to receive the life-saving treatment. An authoritative demand

has to be a last resort, as an expression of despair, and has to be *seen* as a last resort and expression of despair by all concerned.

It might be objected that friendships are too varied a phenomenon on which to base philosophical conclusions. Surely some demented patients have some friends who would 'defend' the patient against the doctor's wish to withdraw treatment, other demented patients have friends who would attempt to persuade the doctor to withdraw the treatment. On the one hand, the objection goes, no general conclusions follow from such diversity; on the other hand, it is also irrelevant to the impartial, objective ethical question of whether the doctor should withdraw treatment. In response to this objection, I have been trying to develop a normative account of long-term friendship which would generate an ethically appropriate response of 'defending' the patient. At the same time, I want to accommodate the possibility that such friends also have the ethical authority to demand that the doctor withdraw treatment as the last resort. In both these ways, I argue that the friend has a real role to play in the ethical problem faced by the doctor.

Conclusion: four objections

The position I have reached is still vague and controversial. I confess that I am not really sure how all this would work in practice—I have very little experience with demented patients or with nursing homes. However, even if I limit my ambitions to adumbrating a structure for further discussion about Dworkin's problem, there remain four powerful objections to such a structure. Let me offer some brief responses by way of conclusion.¹⁶

What if Margo were dazed or distressed most of the time, rather than cheerful?

In all my discussion so far I have adopted Dworkin's (or rather Firlik's) description of Margo as essentially cheerful. But what if the demented Margo, instead of living a life of childish delight, is often or always dazed or distressed? Many demented patients spend the whole day staring and immobile, so that it is not clear what sort of life they are living. Worse, other demented patients are visibly distressed, perhaps from perceived threats or from a general anxiety, perhaps even from brief moments of lucidity where they suddenly understand their bleak situation. Of course the nursing home staff will try to comfort and reassure—and perhaps sedate—the distressed Margo as best they can. But what if Margo is inconsolable? There are many who would

¹⁶ I am grateful to anonymous reviewers for raising these objections.

claim that it would be an act of *kindness* to allow her to die of the lethal but easily-treatable condition, especially given the ‘authorisation’ of the advance refusal.

I have been arguing for a robust presumption that the advance refusal should be ignored, and I will bite the bullet and say that Margo’s distress would generally not, on its own, be a strong enough reason to heed the refusal. I would not let Margo’s very life depend merely on the vagaries of her present mood and experience, especially when the exact content of that mood would be difficult for Margo to articulate and difficult for the staff to confirm. In other words, I would argue that the *certainty* and irreversibility of the consequences of withholding the treatment overrides the *uncertainty* of our understanding of her condition.

This will strike some as cruel, as if I were arguing that Margo should be ‘sentenced’ to a life of distress, way beyond the initial indignity of the dementia. But it is important to remember that Margo’s future might not be entirely predictable; if she is dazed or distressed today this does not necessarily mean that she will be dazed or distressed tomorrow. I concede that if the distress lasted months, if it were possible to reliably discern a more ‘existential’ distress rather than merely physical discomfort (which is more treatable), and/or if it was combined with other co-morbidities such as cancer or a stroke, then a stronger case could be made for allowing her to die.

What if Margo has no friends to ‘hold’ her?

I have been describing Margo’s identity as ‘held’ by her friend, thus giving the friend a special role in the demented Margo’s continuing life, to the point of ‘defending’ Margo against a doctor who might want to withdraw the treatment. I have also acknowledged that a friend might, in extreme cases, have the moral authority to demand the heeding of the advance refusal. But what if Margo *has* no friends or family? Maybe she had friends, but they have stopped visiting her, for whatever reason.

Insofar as the demented patient’s identity is ‘held’ by her friends, I would claim that a friendless Margo will definitely suffer from the abandonment. Of course she might not *appear* to suffer, since she might not notice the lack of visits, in the same way that she might not recognise the friends even if they were to visit her. I have been making a more metaphysical claim, one that cannot be empirically tested. Her lack of friends will undermine the identity she has built up over so many years; and the fact that her former friends do not visit will reveal that they were never serious friendships at all. Both kinds of harm are deeply tragic.

It could be argued that a friendless Margo would be even more entitled to have her advance refusal heeded, since her present experiential interests would seem to have less authority when her present identity lacks the particular

support that only friends can provide. But the same facts of her present friendlessness, I would argue, would make her *more* deserving of ‘protection’ from her past wishes, and from the terrible judgement that her life is no longer worth living. Again, I am starting from the assumption that Margo is basically cheerful, and as a doctor I would find this ethically overwhelming in the manner I described. And as with my response to the first objection, when it comes to the advance refusal I would again say that the certainty of the consequences of withholding treatment would outweigh our uncertainty about the nature of her experience.

The only practical response to Margo’s abandonment would be to place an additional duty on the nursing home staff to get to know Margo while she is in their care, since Margo will be more dependent on them, and on their supportive role as ‘quasi-friends’, than the other patients at the home. I would include friendly contact as a special need among her other physical and psychological needs. This is part of a wider point about the risk of social isolation and the need for companionship, even among the competent elderly, let alone those with any kind of impairment.

Is there a difference with comatose patients?

Imagine another patient named Mark, who signs an advance refusal at 50. At 59 he is involved in a road traffic accident and ends up in a coma. After a year, he develops a life-threatening illness, and the question arises of whether to heed the advance refusal and to withhold the cheap and effective antibiotics. Here I would have much less difficulty in heeding the advance refusal, for the simple reason that the 60-year-old Mark, lying here in front of me, does not seem to have any experiential interests at all, beyond some vague brain activity that is difficult to interpret. Once the diagnosis is made that the coma is ‘permanent’ (typically after a year), then there is nothing in the present to counter-balance the authority of the critical interests competently expressed in the advance refusal. There is no role for a friend to ‘hold’ the comatose patient, because there is no interaction at all, nor the possibility of any moments of lucid recognition. There is no point in decorating Mark’s room with pictures of his former self and friends, when he does not even see them. However much a friend would be tempted to believe that Mark can hear her “at some level” when she speaks, I would here accept that Mark’s life is effectively over. I realise that my position is controversial, and I do not have the space to argue for it, or to offer any new arguments; I am merely stating my position for the sake of comparison with the demented patient.

‘Personal morality’ versus ‘ethics’

Earlier I described the reluctance I would feel if I were the doctor contemplating the possibility of withholding effective treatment and allowing the cheerful Margo-at-60 to die. It will be objected that I was confusing ‘personal morality’ with something different called ‘ethics’. This objection ultimately comes from Kant, and sees ethics as essentially impersonal, as a set of principles that are objective and universal, binding *all* doctors in a given situation regardless of their personal morality. Whether one doctor would feel personally inclined to treat Margo, and another would feel inclined to withhold treatment, Kant would say, is irrelevant to the *ethically* correct course of action that both doctors should follow.

A first response to this would be to trim my philosophical ambitions. Rather than looking for the objective ethically correct course, we could take a doctor who refuses to withdraw the treatment, and enquire into the nature of her reasons for doing so, into the concepts that she uses to make sense of her reluctance. That is partly what I have been doing; but I have also been using my intuitions to argue for a general solution, by trying to trigger similar intuitions in the reader.

There is a larger and more complicated debate here, but earlier I summarised my position by considering the pacifist with a conscientious objection to conscription in a just war. Some philosophers would reject the coherence or the ethical permissibility of such an invocation of conscience precisely because it ignores the objective ethical reality.¹⁷ I, on the other hand, would take the objector seriously, just as I would take her ethical experience seriously as an experience of reality: when discussing her objection, *she* would not distinguish between the ‘personal moral’ and the ‘objective ethical’; the ethical/moral would comprise a single realm that, for her, is objectively discoverable, a realm to which she adapts even at significant personal cost. The fact that another person ethically disagrees with her does not necessarily mean that only one of them can be correct; for to seek ‘correctness’ is already to *assume* the existence of a singular realm of ethical reality to which all are answerable. At the

same time, to reject the singularity of ethical reality does not commit one to an opposing position of radical ethical subjectivism. A middle position is available, but would need much more work to describe. For the moment, I am relying on our familiar experiences of occasional ethical certainty, even in the face of persistent ethical disagreement with respected friends.¹⁸

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¹⁷ For a forceful argument against the legal permissibility of conscientious objection to lawful medical treatment, see Savulescu (2006). It is also worth reading the *huge* number of comments and replies to this article on the BMJ website.

¹⁸ I want to express my gratitude to Dr. Amanda Dalcassian, a consultant in palliative care at the Norfolk and Norwich University Hospital, England, for several discussions about dementia and the medical treatment of it.