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Chapter 11

The Wreckage of Our Flesh: Dementia, Autonomy and Personhood

Thomas R.V. Nys

11.1 Introduction

Could the principle of respect for autonomy – a principle that is considered so essential nowadays – still be relevant in guiding our conduct with regard to people who suffer from severe dementia? This seems particularly questionable because, as a severely disruptive and debilitating disease, dementia erodes the necessary level of competence that is required for people to ground respect for their decisions, that is, they lack the *capacity* for autonomy as a necessary condition in order to enjoy the *right* to autonomy.

So-called advance directives seem to offer a way out of this conundrum as proactive individuals could foresee the dangers of an impending state of disability and non-autonomy and take the required measures to assure that they would never have to live “that way.” However, this road to rescue seems to turn into the proverbial *cul-de-sac* because dementia is precisely unique in the fact that it is *so* debilitating that the individual might have changed her mind. Whether this is cashed out in strong, metaphysical terms (about her being a different person), or just by emphasizing that she has different interests than before, the point is that advance directives do not seem to have a hold – i.e., they do not have the required authority – to guide our conduct vis-à-vis these individuals with dementia.

Recently, attempts have been made to underscore that the principle of respect for autonomy is still very relevant even in people with dementia but that this would *limit* the normative authority of advance directives. The occurrent, contemporaneous autonomy of the patient diagnosed with dementia would render previous ‘living wills’ null and void. Although these attempts are on to something, I will argue that the social nature of ‘selfhood’ as well as autonomy requires a different perspective.

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I will claim that this is the perspective of certain significant others, a perspective that is generally ignored, or underestimated or deemed suspect. Proxy decision-making, however, can be an extension of autonomy and a way to preserve one's personhood. Insofar as some people are worried about these matters, the best solution *for them* (and only them) would be to assign proxies; both because these proxies are in a privileged position to assess the continuity and compatibility of these different life stages, but also because their evaluative judgment *as such* matters to these individuals. On the one hand, this relies on the presence of consent with regard to the assignment of proxies. On the other hand, this 'living will' is more open-ended than it is normally construed as the individual leaves it to the discretion of the proxy as to determine her best interests.

11.2 Two Extremes: Dworkin and Dresser

Ronald Dworkin has famously argued in favor of the authority of advance directives when it comes to morally and legally vindicating the possibility of euthanasia in cases of dementia (Dworkin 1993, 2006). Actually, he offers *two* arguments: one based on the value of autonomy and the other on that of a person's wellbeing. The first sounds rather straightforward. A person has a right to determine her own way of life,¹ and decisions about life and death are indeed life-determining in the most profound way. Dworkin claims – rightfully, as I will hope to argue later on – that an episode of severe dementia can run counter to the way one perceives one's life as meaningful. The state should be neutral with regard to such fundamental choices, that is, it should neither promote nor prohibit their effectuation. Dworkin has used this argument in favor of abortion and procreative choice, but whereas these cases seem far more troublesome, due to the fact that there is a third party involved, the possibility to decide over one's own life seems more convincing.

Now, in order to lead a life of one's own, one has to have a 'coherent sense of self', a relatively stable 'character', and this is what people in a state of severe dementia lack. In *that* particular sense, they lack indeed the necessary competence for the right to autonomy (Dworkin 2006, p. 361). However, the individual with dementia retains the right to beneficence, that is, "the right that decisions are made in [her] best interests...But [she] no longer has the right, as competent people do, to decide contrary to those interests."

Dworkin, however, in a second move, also claims that a concern for the individual's wellbeing would point in the same direction. In this regard, he uses the distinction between experiential and critical interests. These latter interests determine whether my life goes well or not, whereas the first are just about the quality of experience. Now, in the normal case – i.e., healthy individuals – these critical interests

often take, and *should* take, precedence over experiential ones: we value a meaningful life over a mere happy, or pleasant existence. We often endure unpleasant episodes or experiences in our lives in order to achieve some meaningful end, and even if we are sometimes mistaken and we make 'bad' decisions, we still value the integrity that comes with being an autonomous decision-maker over a state in which we are safely kept out of harm's way. Now, from the perspective of critical interests, living in a state of severe dementia – even though happy and contented – could indeed make my life *worse*. In order to serve my best interests then, one should attend to my critical interests when I was still competent.

Rebecca Dresser (2006), in her reply to Dworkin, observes that this might be an elegant theory but that it results in a questionable policy. What it ignores, says Dresser, is the current fate of the person with dementia. We are persuaded to see things from the perspective of the rational person anticipating the onset of dementia and thereby forget that there is a living individual who *does not share* that perspective. In fact, Dresser mentions that the peculiar thing about dementia is that it might radically transform the 'old' person, even to the extent that it turns her into another one. She refers to Derek Parfit's seminal work on personal identity in support of this suggestion (Parfit 1984). If what makes individual X, at t^1 , numerically the same individual as Y on t^2 , is relationship R that shows sufficient continuity over time, then it seems reasonable – due to the devastating impact of dementia on human memory – that the continuity relationship is indeed severely impaired to the extent that justifies speaking about 'different persons'.

What should we make of this claim? Are there indeed different persons involved? Apart from theoretical problems like, "When does this new person come into existence?", or, "When was it born?", I think this is a case in which, in our quest for reflective equilibrium between theory and intuition, the scales refuse to tip in favor of an elegant theory.² If indeed we would change so dramatically as to become an entirely different person, or no person at all, why would we worry so much? Take the case of Margo, the demented individual who is seemingly happy in her condition, reading randomly in her detective stories and enjoying her peanut-butter-and-jelly sandwiches. To argue, as Dresser does, that these insights from theories about personal identity warrant us to take heed of the occurrent demented person's experiential interests, seems to imply that, in the end, we do not take care of *her* wellbeing at all. But her point is that it would be appropriate to Margo, not someone else. So Dresser should be careful in using such radical tools in order to support her conclusions.

Let us therefore put this radical assumption aside and look at what remains of her argument against Dworkin. In general, there are two strands in her argument: one focusing on the limited authority of advance directives, and the other on the limited importance of critical interests. Within this first strand, she develops three counter-arguments. First, many people do not issue such directives and this might indicate that 'such freedom' is not a 'major priority' for them. I do not see how

¹ "...a right to make important decisions defining their own lives for themselves" (Dworkin 2006, p. 359).

² For a discussion of these various problems, see Degrazia (1999).

this argument could provide any force against Dworkin's theory as it was meant to apply only to those who *do* issue such directives.³ Second, people are often irrational when drawing up these directives (by way of including contradictory clauses, for example). But this is not a solid argument either, because we could again stipulate that the authority of advance directives only holds for those that are consistent. Finally, Dresser says that people are generally ill-informed about the prospects of dementia, even in the fundamental sense that cannot know not know what it will be like for *them* to be demented. This problem, which I will call the Problem of Uncertainty, has some force, but *only* to the extent that people are indeed concerned about the experiential side of the disease. I will argue later on that this is particularly doubtful.

The second strand in her argument leaves out the element of autonomy by assuming, for argument's sake, that there are no advance directives. What should we do then? Dresser claims that when others have to determine a person's best interests, they should not privilege her alleged, former critical interests over her occurrent experiential ones. Here it is clear that Dresser does not need any strong metaphysical claim about there being two different persons in order to get her point across. The fact remains that the person – and this could very well be the same person – at *this* time seems to have different interests than the ones she had before, whether or not they are stipulated in an advance directive. She then raises two important concerns: first, other people are quite bad in tracking our critical interests, so they are bound to get it wrong on Dworkinian terms. Let us call this the Problem of Interpretation. Secondly, and this is her central criticism: Dworkin is unwarranted (a) in drawing a sharp distinction between critical and experiential interests, and (b) in giving absolute priority to the first.

So let us take stock. Whereas Dresser does not refute Dworkin's argument for autonomy in case of advance directives, she does mention some important problems, namely the Problem of Interpretation and the Problem of Uncertainty. Most importantly, however, she raises the question of why former critical interests should invariably take precedence over an individual's present, experiential ones. In general, she redirects our attention to the person with dementia. For sure, the more elaborate faculties of these people may have waned, but what remains is a living being capable of pain and pleasure and we should take care of them, alleviating the burdens of suffering and enabling them to live as comfortable as possible.

These two theoretical positions then capture – and indeed *try* to capture – two conflicting intuitions: one about the worries that some people have in anticipating a disease such as Alzheimer's (as it threatens the very concept of a meaningful life) and the other about the fate of the person with dementia, the individual that we face (and have to face) here and now, with particular interests – though perhaps less complex – that we, from a moral perspective, still need to attend to.

³Dworkin, of course, does not argue for involuntary euthanasia (which would be an oxymoron). I will come back to this point as my own proposal concerning proxy decision-making also has this limited scope. It only holds for people who *agree* to such a policy.

11.3 Autonomy on Part of the Person with Dementia

The weakness of Dresser's account is that mere experiential interests on the side of the individual with dementia are insufficient to rebut Dworkin's theory. This is because she does not provide any argument for *why* these experiential contemporaneous interests are suddenly morally authoritative, whereas Dworkin has provided an argument of showing why they are generally less important. In order to address this shortcoming various other authors have tried to emphasize that the principle of respect for autonomy – and not merely a concern for wellbeing – applies to the person with dementia. This would again, and in a stronger sense, limit the authority of advance directives.

Agnieszka Jaworska, for example, has argued that people with dementia retain a fundamental capacity to care and therefore enjoy, what she calls, 'full moral standing' (Jaworska 2007, 1999). Such 'full moral standing' implies that we cannot (that is, should not) interfere with her interests dictated by her caring about certain things. Human beings develop this capacity when they are about 2 years old and they maintain it even in the more serious stages of dementia. Jaworska connects this capacity and the entailing moral status to the notion of autonomy. On her account, what a person cares about constitutes the 'elemental building blocks' of her autonomy.⁴ This capacity to care is what gives us full moral standing and therefore, any violation of this status – by not respecting what we care about – is a serious moral wrong. In fact, Jaworska seems to imply that the notion of 'full moral standing' is intended to denote a person's inviolability. This means that the demented person who has such full moral standing, due to her capacity to care, should not be delivered to the mercy of advance directives which go against her interests as a caring individual.

However, Jaworska also allows for a peculiar asymmetry: although paternalistic interference is unwarranted in case of individuals with dementia, we are allowed to override the full moral standing of young children in order to safeguard, protect, or promote their future wellbeing. The asymmetry is justified by the obvious observation that young children still have a future wellbeing to care about, while people with dementia are only left with this basic capacity to care. This makes sense but it shoots a hole in Jaworska's conceptual framework. The proverbial 'heavy lifting' is not performed by the fundamental capacity to care and the countervailing notion of 'full moral standing', but by this simple asymmetry. In case of dementia, the decay is irreversible; there is no hope of recovery, just a slow decline. Therefore, we have to deal with what is left, not with what supposedly lies around the corner, a mature, competent, rational, fully developed, full-blown individual. If so, however, the individual's mere capacity to care does nothing to invalidate Dworkin's point. Jaworska has merely raised the stakes on the side of the occurrent individual (from experiential

⁴This has an obvious Frankfortian ring to it. In order to be autonomous, the individual's will – her effective desires – should conform with her system of cares. This system is the individual's evaluative horizon, so to speak, by virtue of which she is able to lead a life 'of her own'; this because she is fundamentally identified with what she cares about.

interests, to caring), but she has not dealt with the thorny issue of how previous 'cares' relate to these present ones. I will come back to this point later on.

Sheanna Shiffrin is another author who has emphasized that the principle of respect for autonomy still applies to the person with dementia (Shiffrin 2004). Like Jaworska, she wants to focus on a capacity that goes below the radar if we employ the ordinary standards for autonomy assessment. On her view, autonomy basically means that one has the ability to "control one's experience" and this is something that people with dementia retain for a fairly long time.

Shiffrin also draws an analogy with young children, but whereas Jaworska wants to rescue our intuition that children's interests can legitimately be overruled out of a concern for their future self, Shiffrin reminds us that we often do honor their 'immature' wishes simply because we care about their ability to control their own experience (Shiffrin 2004, p. 205). Indeed, we sometimes allow them to be in control, for example, by letting them choose between different sorts of candy. Now, once again, this basic yet fundamental capacity is all that people with dementia have left. Therefore it becomes even more important as there is no longer any need to compensate for the recklessness of youth in order to safeguard a 'healthy' future self. Respect for autonomy means that we grant them this capacity for control.

With Shiffrin, however, the problem is that she puts the bar too low. If autonomy is basically about controlling one's experiences, then animals would qualify as autonomous as well and therefore command our respect. Perhaps the analogy holds (I unleash my dog in the woods because I grant him/it the pleasure of being in control), but it still taxes our imagination. A more serious problem, however, is that Shiffrin's analogy between young children and people with dementia crumbles as soon as we realize that these latter individuals *were* in fact once fully competent and were perhaps very worried about their future selves. The prospect of a life in which such simple control is all there is left may be a source of deep distress. The same goes for Jaworska. What remains in terms of autonomy, be it the capacity for care or for control, may precisely reveal the nub of the problem: such a life may strike (some of) us as a life not worth living. In my view, by emphasizing a remaining capacity for autonomy on the side of people with dementia, Jaworska and Shiffrin seem to over-privilege *this* side. In my view, they make the same mistake as Dworkin, only in the opposite direction: they think that one can provide theoretical grounds for privileging either one of two possible candidates for respect – the former, competent person vs. the occurrent, incompetent one. I think this is a mistake and that we need to bring out a different perspective that seeks to reconcile these candidates.

11.4 To Care About Something

Let me first come back to Jaworska's contention that the ability to care on the side of the demented person should warrant respect for her current care-informed desires. I do not think that the mere ability to care – or better: the mere fact that one happens to care about something – is enough to warrant something like 'full moral standing'

in the strong sense of inviolability on part of the demented person. Apart from the aforementioned asymmetry (which, as I have indicated does a lot of work in her account) I also believe that Jaworska overstates the *continuity in caring* when it comes to people with dementia. The problem is that, with the onset of the disease, we *stop* caring about a lot of things that used to be very important to us, and we develop new objects of care that would have left us indifferent before. Jaworska, however, seems to employ a Russian Doll model, in which our system of cares, although less complex, would retain the same general features as before. Although this could be true for a large number of dementia patients, it does not account for the possibility that the doll inside, could very well be a *different* doll; one radically at odds with the first.

Jaworska herself observes that caring about something is different from desiring it in the sense that caring somehow extends into the future: caring about something means committing oneself to *keep* caring about that object (Jaworska 2007). In Frankfurt's terms, by caring we seek to maintain some coherence and continuity of ourselves. However, this feature of caring, this link with our 'sense of self', strengthens the Dworkinian perspective, namely that a radical change in our system of cares could be interpreted as a 'loss of self'.

And such changes do seem to be part and parcel of dementia. The most striking example is perhaps that people in the advanced stages of dementia no longer recognize, and therefore no longer care about their husbands, wives, family members, close friends and relatives. And, as an example of a 'new' object of care that emerged with the onset of the disease, we could refer to the famous case of Iris Murdoch who suddenly took a great interest in watching the TeleTubbies.

This criticism also gains strength if we look beyond the Frankfurtian paradigm and acknowledge that we deeply care about – not merely about coherence and continuity – but also about *what* we care about, that is, about the *quality* of our cares. As Susan Wolf points out, we indeed want our children to care about something so that their lives will be imbued with importance, but it is not that we advise them to just "care about what they can" (Wolf 2002). Young children counting blades of grass, or torturing small animals, is generally considered as 'sad' or 'disturbing' rather than worthwhile or valuable. If so, then this extends to our future self as a demented person: we do not want to be engaged in or 'captivated by' such meaningless activities. In short, the focus on the capacity to care can easily be turned against Jaworska's project.

11.5 A Look Ahead

Even though I believe that the arguments of Jaworska and Shiffrin fail, I do think that we should attend to the identity and autonomy of the individual with dementia. In fact, this is what close friends and relatives often do. But they do so, not just by focusing on the 'here and now' (although they do, of course), but by relating the present state of the person with dementia – her current cares, desires and wishes – to the way they remember the person, that is, to the way she was *before* the disease kicked in.

I will try to provide a normative underpinning for this practice in the next section, but for now, I just want to anticipate this idea of what it means to respect the autonomy and identity of a person with dementia.

For example, many authors point out that good care for the demented person involves the preservation of personhood (Buron 2008; Murray and Boyd 2009) and the support of autonomy (McCormack 2002). McCormack, for example, emphasizes the above-mentioned ‘Russian doll model’ of autonomy, but he shows how this is not a matter of continuous cares (by which the occurrent cares are remnants of the old ones) but that caretakers actively need to ‘chip away’ beyond the person’s overt behavior and look for hidden emotions and beliefs. Respect for autonomy (or, as he calls it, authenticity) requires such chipping away: it requires effort and interpretation in order to discern those remaining elements. Also, such interpretation demands sensitivity to the person’s life narrative.

He gives the example of Susan, who was once “an independent woman, a professional who was always in control of her own decisions and choices” but who is now in the mid-stages of dementia. Her story is now in need of interpretation. As such, it may not be a ‘rational narrative’ but it contains:

...a *cachet of truth*, i.e. [...] elements of the person’s past life, their biography and autobiography and those of others around [her]. Susan’s narrative is consistent with her previous roles in life, as a professional woman, a wife and a person whose family and friends knew to be dedicated to independence in all aspects of her life (McCormack 2002, p. 118).

On the other hand, John McMillan gives the example of Mr. D, a former classics teacher, who, over time became less affectionate to his wife due to his condition of dementia.⁵ His wife, Mrs. D says “He’s not the man I married – that man has been dead for at least two years.” The question is whether Mrs. D is indeed correct: does it make sense to say that the old Mr. D is gone? McMillan claims that it does. He draws on the work of Charles Taylor and concludes that “our webs of interlocution are the foundation upon which our sense of self or qualitative identity is formed and that a typical instance of self-articulation involves developing a first-person narrative about our web of interlocution” (McMillan 2006). But Mr. D is no longer capable of telling such a first-person narrative. Yet, McMillan observes:

Given his past dedication to family and marriage, his wife’s views about his change are crucially important. She has been married to him for most of their lives and knows, possibly almost as well as the pre-dementia Mr. D would have known, what his webs of interlocution or frameworks of value were. So she is in a good position to give a narrative account of his agency and how dementia has damaged it (McMillan 2006, p. 69).

Even if the person herself no longer has access to her narrative or is unable to communicate it, there are certain ‘significant others’ around her that can make valuable assessments as to how a life with dementia relates to this general life story. The question, of course, is what role such significant others could or should play in deciding for the person with dementia. What these authors have stressed is the

⁵ The case was originally described by Tony Hope (1994).

importance of restoring or protecting personhood in taking care of people with dementia. If we are concerned – as we should be – about their quality of life, then this focus on personhood is very important (Murray and Boyd 2009).

11.6 Socializing Autonomy

What I said in the previous section makes clear that respecting the autonomy and personhood of people with dementia is a matter of assistance and interpretation. Jaworska and Shiffrin may be right that the embers of autonomy are still glowing but we should add that it takes effort to get the fire burning again. Moreover, it is a matter of interpretation in light of the person’s individual history and not a mere case of respecting occurrent cares. More precisely, to find out what a person cares about right now, is to interpret what she *seemingly* cares about in light of her life story, that is, taking into account “who she used to be”.⁶ Now perhaps Jaworska meant just that or, at least, she presumably does not want to exclude such interpretative assistance (although she may be afraid of such translation being distortive of the occurrent, salient ‘cares’ of the person with dementia). Nevertheless, I also believe that one might discover that the ‘cares’ of the old and the new self, as in the case of Mr. D, have radically come apart, and that it is impossible to reconcile these two stories without having to admit that the story of the present, demented self is fundamentally at odds with the way one envisioned one’s entire life. I have therefore briefly indicated how others – caretakers, friends and family members – try to preserve the personhood and autonomy of the individual with dementia.

In this section, however, I want to return to the point of view of the individual herself and how this perspective is influenced (and even constituted) by social elements. There are many ways in which the notion of autonomy has been ‘socialized’. A fairly straightforward way to bring out the social aspect is to say that autonomy requires some form of critical reflection and that this ability itself requires a social embedding, or environment, for being developed in the first place. Without some minimal level of education, for example, no-one would have the tools for critically assessing one’s own desires or beliefs. This is something we learn, and we learn it from others (most notably, our parents). Crudely put: children ‘raised’ by wolves would not develop such a capacity. Also, the way we are, or “who we are”, our personality – if you like – is the upshot of various social forces. In fact, it has been questioned whether there still is a self, or philosophically speaking, a ‘subject’, once we acknowledge the interplay and influence of such forces beyond our control. Anyhow, it is clear that we do not create ourselves *ex nihilo* and that critical reflection

⁶ Bert Keizer, a famous Dutch physician and philosopher, once, during a workshop, gave the example of a woman with dementia who was unable to communicate her wants without the assistance, that is, interpretation and translation, of her husband. He had to help her in communicating her preferences to her caretakers. I believe this is a clear example of ‘assisted autonomy’.

takes as a starting point or background, something which is given rather than created. Therefore, if autonomy essentially means self-determination, then the social nature of the self implicates a socialization of the notion of autonomy. A third way to 'socialize' autonomy is by pointing out its *relational* aspect. Although 'relational autonomy' is an umbrella concept that is used by a variety of authors, it signifies that the individual's autonomy is a matter of the right social relationships between different individuals (Mackenzie and Stoljar 2000). As I mentioned above: the capacity for critical reflection could only develop by virtue of a social environment that indeed fostered or inculcated this capability. In this case, however, the required social relationships are only causally necessary for autonomy. But they could also be *constitutive* of that capacity: for example Axel Honneth and Catriona Mackenzie stress that the required relationship-to-self can only hold if one stands in the appropriate relationship-to-others (Honneth 1995). In order to be autonomous and have normative authority, one has to possess the required self-trust, self-respect and self-esteem and this is impossible without the social recognition of others.

Although these accounts are very interesting, I want to draw attention to a slightly different way of 'socializing autonomy'. It ties in to the Hegelian theme of recognition in the sense that the manner in which the individual perceives of herself is dependent upon due recognition by others. The projects, values, and commitments I endorse – the ones that I identify with, and that identify me – are only valuable to the extent that they are vindicated by others. We do not *create* such value simply by virtue of the act of endorsement. This requires a horizon of significance – to use Taylor's famous phrase – that lies beyond the individual's direct control. Now, both Hegelians – that is, Honneth as well as Taylor – take their cue from Herbert Mead's seminal work on the role of so-called significant others and they develop it (or at least fit it) into an encompassing philosophical framework about social recognition.

For the purposes of this paper, however, I want to stick to this – if you may call it – psycho-philosophical point about the role of significant others. The central mechanism is that we, as individuals, interiorize the perspective of these significant others. We evaluate ourselves in light of their perspective. This is obviously related to the point I made earlier: I can only hold my projects, values and commitments to be valuable if and only if others validate that significance. It is also related to the remark that our 'self' is social in nature, though not because it is entirely swamped by social or natural structures or forces, but because in our own 'private' evaluation we take up the roles of others. The struggle for recognition, then, is a struggle for *their* recognition as constitutive of *our* own identity. The essential point is that for me to exercise my autonomy, to lead the life I want to live, to be committed to projects that I deem valuable, to which I subscribe and which I endorse, I am crucially dependent upon this inter-subjective interplay.

Consequently, as this has repercussions for the way we think of our 'selves', this has ramifications for autonomy as well. We want to be determined by 'what we care about', but this 'what' is not justified by our mere caring about it, we want it to be *worth* caring about and this requires the recognition of others. As I mentioned before, a person could dread the moment when she would no longer care about her family because it is constitutive of who she is. To lose this care is to lose herself. The cares that are left in this future scenario – watching endless episodes of TeleTubbies,

dozing in the sunshine, eating peanut-butter-and-jelly sandwiches – do not make up for that terrible loss. In fact, we do not want to care about such worthless things. What I have added to this account now, is that this value judgment is tied in to this social dynamic, in which significant others play a crucial role.

Normally, during a lifetime, the individual retains a dialogical relationship with these significant others. She does not merely interiorize or absorb the others' evaluative perspective. One does not seek recognition through sheer conformity, but the dynamic takes the form of a genuine struggle, that is, an attempt to persuade others of the worth of one's desires, values and commitments. When severely demented (i.e., while incompetent) this dialogical character dissipates in the sense that one is no longer actively engaged in this struggle. In fact, I believe this is a major source of concern for some of us, and I will come back to this point later on. What remains, however, is this social background, the evaluative *milieu* that provided a web of interlocution (and that was indeed McMillan's point in the previous section). Therefore, I agree with both Jaworska and Shiffrin that we should deal with 'what is left', but we should not only look at the remaining capacities on the side of the individual, but also take into account this social fabric that was (and *is*) constitutive of one's identity.

The problem is that we, in cases of *severe* dementia, no longer seem to care about what is worthwhile or not. We just happen to care about certain things, and that's it. On my account, it is not just this bare capacity to care that really matters, but the capacity to care *about* these cares. To the extent that this dimension of evaluative reflections has disappeared, the Dworkinian perspective again gets the upper hand. The problem, however, with Dworkin's account was that it did not pay sufficient concern to the perspective of the person with dementia. So we need a vantage point that relates these two 'selves'.

However, the problem of a 'divide' between the two standpoints is particularly clear in what I called the Problem of Uncertainty. People who draw up advance directives make clear that they do not want to live 'that way'. Critics like Dresser, however, will point out that they do not know what it will be like to live 'that way'. They might think it is dreadful *now*, but it might turn out to be not that bad after all. In fact, in some cases it seems indeed that a life with dementia can be without pain and distress and be characterized as 'relatively comfortable'. Now, several remarks are in place. First, advance directives normally take the form of 'if-then' clauses. A person could therefore stipulate that, in case of such a 'happy' development, her desire for death should have no authority. Secondly, and more importantly, the phrase 'I do not want to live that way!' is confusing, because the quality of life 'on the other side' is seldom the issue. One does not fear being in pain, or being unhappy, but being somehow 'out of touch'. Let me elaborate on this phenomenon.

11.7 The Wreckage of Our Flesh

Why do people dread the prospect of severe dementia? This question is impossible to answer in any conclusive statement. Some people may not dread it at all. They may accept it as a natural part of life. Perhaps they would prefer to be spared of the

isease, but if so, 'que sera, sera'. If there is any strength to the liberal-Dworkinian outlook, it is that it provides room for different conceptions of the good, and that it does not require people to share the perspective that a life with dementia is somehow unworthy or demeaning.

Of those who indeed dread the prospect, there could be people who want to avoid the pain,⁷ or the confusion and bewilderment, or the general state of anxiety to which some persons with dementia are prone. In short, they may indeed shiver at the prospect of 'living that way', defined in experiential terms. It seems terrible to them to be afraid all the time, to see strange faces, and feeling haunted and wanting to escape. I do not believe that these fears are totally misdirected, and to the extent that they are not, this provides us with a third additional reason to withstand the Problem of Uncertainty. Although interesting from a theoretical point of view, we should not exaggerate this problem in practice. Thomas Nagel may have rightfully questioned our ability to answer the question 'What is it like to be a bat?', but the prospect of dementia is not that opaque. We do know that dementia can sometimes be a horrible state of mind.

Even so, I think Dworkin is correct in saying that we are not so much worried about the way it would *feel* to be demented, the way that we would *experience* the state of dementia. It is not so much that we are worried about what goes on inside, so to speak. We are worried about the fact that we have somehow lost touch with the things we deemed essential of ourselves, that we have lost touch with reality, with a world of meaning and importance. Just being demented – no matter how pleasant it could be – indicates a loss of self. It is the fear of us somehow living on as not-us.

People with dementia are sometimes described as 'living dead' (Buchanan 2001). What this hyperbole is meant to convey is the idea of a mere existence, not quite on a par with a 'life'. As my dramatic title suggests, the image that some of us might fear in dementia is that of the wreckage of our flesh just drifting about aimlessly, with no point or purpose, while we have lost all control over the way in which this driftwood may collide with the things we held so dear in life. But, of course, we don't know if and to what extent such a collision will take place. And this is where others enter the picture. For some people then, proxy decision-making is highly appropriate (and not just second-best).

Let me distinguish three ways in which the perspective of others can be crucially important to us when we are diagnosed with dementia. First, we sometimes care about what these others care about in the most obvious sense, namely that we would not like to be a burden to them. This is so because we care about them. Also, if we could still bring some joy to their lives, death would not be necessary; our life would still be worthwhile. Notice, however, that such joy is never sufficient: even if there is evidence that these others would be quite alright with us being in a state of dementia, this does not imply that – because of this – we should be kept alive at all costs. My point is merely that the evaluative standpoint of others is often relevant in deciding what should happen to us in a state of severe incompetence.

⁷ There does seem to be reason to be worried about pain management for people with dementia (Malloy and Hadjistavropoulos 2004).

Secondly, we also value their perspective because they are the best available judges of our lives' continuity. This is, in fact, what we expect these proxies to do: that is, to assess whether some decision or option is in line with our character and personality. As they are familiar with 'who we were' and 'who we wanted to be', as well as with who we are *now*, they are in a privileged position to judge whether some course of action is either in line or 'out of synch' with our way of life. They are indeed the safe keepers of our personality, as the examples I mentioned above were meant to indicate. They alone are able to bridge the gap that separates the old competent self from the now-incompetent one. They were there when we were fully competent, and they are still there when these critical capacities have waned.

However, their incompetence in these matters has often been emphasized. It turns out, as Dresser notes, that many of these surrogates would take *different* decisions than the ones we would take ourselves. This was the Problem of Interpretation. Apparently others are not that good at articulating what are supposed to be our wishes. One way to respond to these accusations is pointing out that this imperfection is made good, is compensated, by their privileged position 'on the other side' of the competence divide. They may not be capable of perfectly tracking our point of view, but they do know something that we do not: they are there to compare the condition of us as a demented person with the one that was still unaffected by the disease. However, it could be further questioned, if such 'perfect tracking' is indeed what they are supposed to do. Those who choose to rely on proxies, I guess, value the perspective of others, as mere evaluative beings. And this would be a third way in which proxies are important. We appreciate the way *they* would evaluate our condition, and not just how they would think *we* would assess it. This ties in with the earlier remarks about our identity and the need for recognition. It matters to us if they would deem our life undignified or horrible, for example. Notice that this has nothing to do with the way that our existence as a highly dependent being affects their lives (that is the question of it being a burden or a joy to others), but about a value judgment that is independent of such other-regarding concerns. It is the mere perception of our life being somehow worth living or not, that matters to us.

So, it is not about the experiential side of the disease, nor do we want to make sure that they would decide as we would have done (again, we would have drawn up an advance directive, but how should we know all the relevant details?), but about the way others – some important others – perceive of the value of our life. This because already while fully competent, 'alive and kicking', we construct and shape our lives in a perpetual, ongoing dialogue with these significant others.

Let us take our inspiration from horror movies, one more time (the living dead, remember). The effect of dementia, of the disease slowly destroying our memory, is akin to the experience of walls closing in on us. Now, whereas in these movies part of the horror consists in the victim being a powerless witness to her own gradual, excruciating demise, in case of dementia, we are sometimes (yet, not always) spared from the cruelty of spectatorship. We do not have to be aware of us gradually losing all sorts of abilities. However, what remains is the uncomfortable fact that *others* will indeed be spectators to our decline.

Now, if there is any truth in this description of the concerns that some people have regarding dementia, then this indicates a standpoint that is able to surmount the standoff between Dresser and Dworkin for *it fundamentally shows the importance of others in the decision-making process in case of dementia*. As such, it solves the Problems of Uncertainty (because the experiential question is irrelevant) and the Problem of Interpretation. The latter because interpretation is not a threat to our supposedly 'true wishes' – i.e., others being unable to track them, contaminating them with their own views on things – but an integral part of what we want them to do. Dresser's remark that not many people draw up advance directives but instead rely on friends and relatives indicates perhaps not that they rely on some second-best standard, but that they do not expect them to approximate or mimic their former self. Notice that many of these surrogate decision-makers will do just that, and try and pay justice to the individual's own conception of the good, but the fact that they incorporate their own views is not a matter of unfortunate contamination. We do not expect them to shed their evaluative skin. It matters to us how they perceive our situation, whether they can still retain our self under these new conditions. This account then does not privilege either the former competent individual's perspective or the one of the present individual with dementia. What matters is how these different episodes interact, or make sense, in the eyes of these significant others.

11.8 Replies to Some Possible Objections

To conclude, let me briefly respond to some anticipated objections. To some it may seem as if I give too much power to others in deciding what should happen to people with dementia. Notice, however, that I do not claim that all individuals have these worries that I describe. Like Dworkin, I want to provide a normative underpinning to those who have such concerns. I do not in any way want to promote this approach to those who do not. Unlike Dworkin, however, my proposal does not rely on any hierarchy between critical and experiential interests, nor do I want to maintain any strict distinction between them. Yet, I do agree with him that to show respect for autonomy, these surrogates or proxies should somehow be appointed. And this may solve a second worry, namely "Who would have to take these decisions?" The answer is: those that we deem fit for the job. We may be mistaken, of course, about their capacities and intentions, but since people diagnosed with severe dementia are highly dependent upon assistance, I fail to see how we could eliminate such 'defective help' altogether. When I say that proxies should be assigned and therefore that this assignment is a matter of respecting one's autonomy while fully competent, I nevertheless wonder whether such assigning should require an explicit act of authorization or whether there can also be some kind of default option (e.g., one's children as default proxies) with the possibility, of course, to opt-out. Such a default would be justified, presumably, because we generally have a good idea of who these 'significant others' are (and who will be around when at the time of need). This is an empirical question. Finally, I must admit that my approach is not in any way new or groundbreaking.

Family members, for example, already have a say in the treatment of their relatives with dementia. What I intended to do is to provide some theoretical grounds for that authority and to question the common suspicion that befalls such proxies, whether as a poor substitutes for indicating the individual's own wishes, or as self-interested, and therefore not-to-be-trusted parties in the debate.

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