Chapter 10
The Authority of Advance Directives

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10.1 The Problem

In my wallet I always keep my membership card of a road service company, my organ donor card, a blood group card, and a ragged piece of paper stating my living will.

> It is my will to live no longer and die in a humane way in the event of my entering into a mental or physical condition that offers no or hardly any prospect of returning to a state of life that I consider acceptable and dignified.
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> 1. If this condition should occur I hereby refuse my permission for any life-sustaining treatment.
> 2. If I should be unable to die shortly in a humane manner as a result of abstention from (further) medical treatment I hereby urgently request the doctor attending me to fulfil my wish to die by administering to me the medication that will ensure a humane death.

And by this condition I mean, among other things: "the permanent and (almost) entire loss of my ability to perform mental activity or to communicate or to live an independent life". What I have in mind is of course an advanced stage of Alzheimer or another form of dementia.

But do I honestly think that both these stipulations, the negative as well as the positive advance directive, will be honoured when the moment arrives? I do believe there is a real chance that the negative stipulation (refusal of treatment) will indeed be observed when it applies.[1] Although intensive care specialists still routinely

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[1] All states in the USA have legislation governing advance directives, as do most of the Canadian provinces, a number of Australian states, New Zealand, and a number of European countries, including Denmark, the UK, the Netherlands, Belgium, France, Spain, Austria, Hungary, Serbia, Georgia and recently Germany. The Netherlands is the only country which gives some legal status to positive advance directives.

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brush aside such clauses when they have to decide about re-animation after an accident or stroke (Kleijer 2005, pp. 100ff),[2] nursing home doctors appear to take them somewhat more seriously, perhaps out of a more intense personal involvement (Vezzoni 2005, ch. 7; The et al. 2002; van Delden et al. 2011, pp. 151ff).[3] My confidence is greatly increased, because my living will also identifies legal representatives whom I can trust to know my interests well and to be active in promoting them. As regards the positive provision (request for termination of life), however, I have hardly any illusions. Although the Dutch euthanasia law makes it possible to determine, on the basis of the living will, that a 'voluntary and well-considered request' has been submitted, the rest of the requirements of due care still need to be met. And until now it has been the general view of the medical community, confirmed by three authoritative documents, that the suffering which results from dementia cannot by itself be considered unbearable, as the law requires (KNMG 1997; NVVA 1997; Gezondheidsraad 2002). According to these documents any severe suffering demented patients may experience results from symptoms caused by other disorders. Not surprisingly, then, so far no cases of euthanasia on patients in an advanced state of Alzheimer have been reported to any of the euthanasia review committees, although in recent years the number of cases concerning patients in a early stage, who are still able to express their requests, has been rising, to 25 in 2010 (Regionale Toetsingscommissies 2011).[4]

So why have I put that clause in my advance directive? What am I so afraid of, do I have exaggerated ideas of the suffering that awaits an Alzheimer's patient? One of the most common criticisms of the authority of advance documents is that the people who sign them do not, perhaps even cannot really know from the inside what it means to be in an advanced state of dementia, and hence act on unfounded fears (Dresser and Robertson 1989; Buchanan and Brock 1990, p. 153; Hope 1992; Dresser 1995, p. 34, 1984, 2003,; Fagerlin and Schneider 2004; Fried et al. 2007; and other authors referred to by Levi and Green 2010).[5] However, when I first took such a document with me, somewhere in the early 1980s, the thought of future suffering was hardly on my mind at all. In the meantime, it is true, I have begun to appreciate that it is indeed a horrible thing to become aware, or merely dimly suspect, that you have entered upon an irreversible process that will end in a complete

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[2] Family doctors have similar attitudes (Vezzoni 2005, ch. 8).

[3] It may be that the availability of a negative advance directive doesn't make much of a difference in this case because nursing home doctors are inclined to act as they request anyway, even without being requested (Teno et al. 1994). But according to van Delden et al. (2011, pp. 151 ff), Dutch doctors tend to take the directive into account in identifying the relevant values of the patient, and hence his 'best interests', even if most of them don't know that it is (*pro tanto*) legally binding and, even if they know, don't recognize its authority.

[4] Only recently for the first time an appeal to the living will has been made in such a case, because the consultant and the review committee considered the patient incompetent at the time of his actual request. In all other cases the actual request has been assessed to be well-considered. Only 20% of Dutch doctors know that the law does not require this to be the case (Van Delden et al. 2011, p. 165).

[5] Berghmans (1998) calls epistemic failure inevitable.

loss of your mental faculties and hence of your independence and perhaps to become a burden on others. By now I also believe that the permanent confusion and disorientation to which you will probably fall prey in the subsequent stages of that process, your inability to put on your shoes, the fear and paranoia, constitute very severe suffering. I well remember my mother-in-law being restless all the time, for hours on end looking for her coat and the front door since she wanted to go 'home', meaning her parents' home. Hence I believe that the view that a demented person cannot be considered to be suffering unbearably, at least not as a result of the dementia, needs reconsideration (see Sect. 10.4 below). But the fear of suffering is still not my main motive for carrying an advance directive. My dread of losing decorum is certainly relevant as well. But even if I would do nothing *then* of which I would *now* feel ashamed, I still would not like that final stage of my life to be a part of *my* biography. What scares me is the peeling away of my self, the gradual loss of everything that was important in my life. I would not want my grandchildren to remember me in the way in which my own children remember my mother-in-law. Both to be in that state and to be perceived to be in it would, I believe, taint my life (Cf. Nys 2012 in this collection).

The usual reaction to these motives is that my attitude may be understandable in a professor who thinks that life has no value if he is no longer capable of writing big books that nobody reads. But what typifies the whole process of becoming subject to dementia is precisely the fact that this peculiar system of values will irretrievably disappear and this self-conception be completely effaced. Even when I first have to go through a stage of suffering, that stage will pass. A moment will come when I will sit in the sunshine and doze off and not even remember what a book is.

In a column in a medical journal Frans Meulenberg tells the story of Iris Murdoch watching Teletubbies, and a number of similar dramatic tales of loss. He comments: becoming older is attended by much loneliness and sorrow, but the shrinking of the brain prevents us from experiencing it all. No process of de-humanization, then, rather a protective mechanism to secure our happiness:

> Horrible? Grotesque? Tragic? Degrading? It depends on how you look at it. The Teletubbies, after all, doubtless bring joy to the demented. What's wrong with that? Man is just a happiness-seeking animal (Meulenberg 2006).

Why should we treat people according to the conceptions of their past self? We would then accept that this earlier self tyrannizes the later self.[6] An advance directive would have the effect of tying oneself to the mast like Ulysses. But why should we regard the sweet call of life in the case of the elderly suffering from Alzheimer's as a Siren's song?

This is how the problem of the authority of advance directives has been posed in the literature: as the question of who has the final say on the matter, the earlier or the later self. Although some of the authors who thus formulate the problem make courageous attempts to save the authority of the advance directive, I fear they are waging a losing battle. After all, the person doctors are confronted with and

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[6] Dresser (1984) calls this 'self-paternalism'; cf. Davis (2004).

probably the only one they have ever known is the Alzheimer patient, and it seems unthinkable to disregard his actual will and his actual interests on the authority of a piece of paper representing a will and interests he no longer shares. My main argument in this paper will be, however, that the problem is wrongly posed in this way. With one important exception (Sect. 10.5), there is no conflict of will or interests between different stages of the self.[7]

I have given the problem I want to discuss a first-person formulation. My aim was not so much to alert my readers to my personal interest in the matter, although I think it is only fair that they know. I have mainly done so to neutralize from the start a standard objection against recognizing the authority of a living will in such cases: that this reveals a depreciation of the life of the mentally less gifted.[8] I'm not talking about the value of other people's lives (the value it holds to themselves) but about the value, to myself, of a possible stage in my own life. Such personal interests cannot be determined independently of a person's own priorities. My priorities are different from Meulenberg's. For me the prospect of being happy with the Teletubbies would not detract from the horror; it would rather be its culmination.

But could I not be mistaken in my priorities? Or, for that matter, could Meulenberg not be mistaken in his? I do not deny that, even if personal interests are to a large extent dependent on personal values, personal values can be criticizable themselves. But even in that case, I will argue, both Meulenberg and I have the right to be treated in accordance with our own mistaken views.

10.2 The Structure of My Argument

The discussion about this subject has been dominated during the past 15 years by an impressive chapter that Ronald Dworkin dedicated to it in his book *Life's Dominion* (1993).[9] Dworkin makes a distinction there between critical interests and experiential interests. Experiential interests are interests you have in the quality of your experience, from moment to moment. Do you on the whole feel well or badly? Critical interests are interests that are based on a value judgement about your life as a whole. My advance directive, says Dworkin, must be regarded as an authoritative representation of my critical interests. What I value is ending my life in a way which

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[7] When Davis (1999) advocates pre-emptive suicide for people who expect their advance directive to be disregarded, Gedge (2004) even interprets this as an act of aggression of the former against the later self, as do Hertogh et al. (2008), in their reply to critics. That of course presupposes that the later self has the will to live or at least an overriding interest in survival. Davis' worry, however, concerns people who are prepared to overrule *her* authority because *they* have such beliefs as regards later selves.

[8] Such views do not take into account the fundamental difference between the personal value of life, that is, the value life has for the one living it, and a possible impersonal value (Cf. Sect. 10.7 below).

[9] An important predecessor is Rhoden (1990).

is consonant with the character of my life as a whole, just as one might want a play to end with a scene that fits the play as a whole, or a poem with a stanza that brings the work to an appropriate climax. On the other side of the balance we only find the frail happiness of some pleasant moments the Alzheimer patient may still experience. Critical interests, however, carry more weight than experiential interests, and therefore my advance directive has authority.

Dworkin's argument has been countered in two ways.[10] The first option is to deny that experiential interests must always give way to critical interests. The second one is to argue that the patient suffering from Alzheimer's still *has* critical interests of his own. Meulenberg's comment on Iris Murdoch enjoying the Teletubbies presupposes her to be a mere passive recipient of fragmentary and fleeting pleasant and unpleasant experiences who has lost every sense of self. But until a late stage[11] that patient is still interested in issues outside him, including other people, and acts on the basis of that interest, often in ways which can be recognized as simplified variants of her earlier patterns of behaviour, and therefore as an expression of a personality that still exists.

On closer consideration these strategies do not really exclude each other because they seem roughly to apply to succeeding stages of the disease. The remnants of the self are gradually broken down until the patient really only has experiential interests. We have therefore to consider the authority of advance directives in both stages. I will do this in Sects. 10.3 and 10.4 respectively. In addition I will discuss (Sect. 10.5) the objection that, even if my living will is not opposed by my present interests as an Alzheimer patient, it may be opposed by my present will. It is at this point that I will be prepared to accept an exception to my general thesis.

People like me who want to uphold the authority of advance directives, at least to a significant extent, are often accused of an inflated respect for personal autonomy, as the one and only relevant value in this area (Dresser and Whitehouse 1994; Widdershoven and Berghmans 2001; Dawson and Wrigley 2010). In my argument the appeal to that principle, however, will have no central role to play. Basically that argument will be that, given the values to which my life as a whole has been oriented, it will be in my interest to have my living will executed. That interest should not be conceived of as merely the interest of a past self standing opposed to the interests of a present self. It is only to those who protest that I am mistaken in my view of my own interests that I will reply (Sect. 10.6) that in the end that doesn't matter. It is at that point, and only at that point, that, properly speaking, I will argue for the *authority* of my advance directive. For by allowing someone to have authority you recognize that his decision stands, even if it is mistaken.

It is important to distinguish between these two possible roles of living wills. They provide evidence concerning the relevant personal values in terms of which

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[10] A third is to argue that the critical interest is only the interest of the former person, which now has been replaced by the interests, critical or only experiential, of the present individual. I consider that argument in the first paragraphs of Sect. 10.6.

[11] Perhaps to be identified with scale 7 on the Functional Assessment Staging Scale (Mitchell 2007).

we have to understand a person's best interests. And they claim to be a binding representation of those interests, whether or not they represent them correctly. In regard to the first role it is standardly said that they allow us to act on the substituted judgment of the person, but that notion actually confuses the two roles. You can only act on someone's authority when that authority has been exercised, and a person's commitment to certain values is not an exercise of authority.[12]

Even if my living will should be seen as an authoritative representation of my interests, and if this applies to the positive clause as much as to the negative one, it doesn't follow that doctors are morally required, or even permitted to comply with it. Other relevant values may be at stake. I discuss this possibility in my final section (Sect. 10.7).

As announced I will argue that on the whole it is a mistake to believe that in deciding whether or not to comply with a living will we have to take sides in a conflict between two stages of the self. But I will put aside one radical way to deny that there may be such a conflict: by denying that there is one self. Relatives of patients in an advanced stage of Alzheimer's sometimes say: "That is no longer my husband, my mother". They mean to say this metaphorically, but couldn't they be right literally? Isn't there a point in the demolition of the self at which the connection between the present individual and the former person has become too thin to hold that they are stages of the same being? In that event the advance directive would have no authority whatsoever (Dresser and Robertson 1989; Wrigley 2007). It seems preposterous to claim the final say about someone else's life.[13]

When do "I" start to exist, when do "I" cease to exist? What constitutes my numerical identity? That is a fascinating topic, but it deserves a separate treatment. In this paper I will just assume that I am the same person, or at least the same being, as the future Alzheimer patient carrying my name, that my relatives will make no mistake in celebrating my anniversary and not starting to apportion my estate, and that my concern about getting into that stage is entirely warranted.[14]

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[12] On content-independence as the essence of authority see den Hartogh (2002, ch. 7) with references.

[13] Buchanan and Brock (1990, ch. 3) and Kuhse (1999), however, suggest that a person may have authority about the fate of his post-person successor, his "living remains", just like he has authority about what happens to his estate and his mortal remains. But we do not normally consider even radically incompetent people to be at the disposal of others in this way; they have interests of their own and therefore moral status, whether they are persons or non-persons.

[14] I will also put aside some pragmatic objections commonly made. The most common objection probably is that advance directives do not enable a doctor to identify a unique decision because they always require interpretation (E.g. Widdershoven and Berghmans 2001; Gastmans and Denier 2010). It is worth observing about such doubts that they invariably only reflect a worry of possibly being too early, never of being too late. Of course I do not dispute that advance directives may be so inadequately formulated that they are of no use at all, see for an interesting example Crippen (2000), and commentary by Truog. However, every law requires interpretation, but only legal realists think that this implies that judicial decisions are not constrained by law. According to research by Rurup et al. (2005) doctors generally are able to recognize the conditions for which the living will has been made. Their claim to the contrary as registered by other researchers may mainly reflect a reluctance to comply with it. Because of this common reluctance, it is essential to give the durable power of attorney to a trusted friend or relative, and extensively discuss future decisions with that person.

10.3 The Experiential Interest in Survival

When I drew up that advance directive, I thought, as I told you, of the implications which a period of increasing dementia at the end of my life would have for my life as a whole: a gradual disintegration of my person leaving me a mere ruin of my former self. One could look at it as a way of slowly dying. But once I arrive in an advanced phase of Alzheimer's, I will not be able to think in that way anymore. When that happens, at a certain moment only the quality of my experiences from day to day will count for me: the days will be bad when I suffer and relatively good when I feel well.

Suppose I am on the whole pleasantly demented. Should my supposed critical interests still take precedence as a matter of general principle? Should I always be treated in accordance with the values which I have subscribed to during my life as they could be discovered by 'reading' the story of that life?

Maartje Schermer discusses the not uncommon case of a woman who has always, throughout her life, put great value on good appearances, but who in the nursing home opposes all attempts to make her look a bit decent (Schermer 2003).[15] For Schermer it is of major importance that the attempts to force her into the system of her own previous values not only withhold something good from her, but positively cause anguish. It also seems relevant that the reason why it is important to you to look good is that you derive some self-respect or self-confidence from that. But that is no longer possible if you can no longer see yourself through the eyes of others.

I agree that in general critical interests do not necessarily prevail over experiential interests. For that reason we should probably disregard an advance directive instructing us not to provide palliative care to a severely suffering Alzheimer patient, even if we could understand the directive as deriving from the fundamental values she has subscribed to during his life. However, the question now is about the interests one can have in *continuing* one's life. If an Alzheimer patient still has a positive hedonic balance from day to day, is this sufficient to conclude that for the time being she has an interest in survival?

This question could be rephrased in terms of the famous Epicurean challenge. Let me quote Epicurus himself from his letter to Menoeceus:

> Death is nothing to us. For all good and bad consists in sense-experience, and death is the privation of sense-experience. That knowledge makes the mortality of life a matter for contentment, not by adding a limitless time to life but by removing the longing for immortality. For there is nothing fearful in life for one who has grasped that there is nothing fearful in the absence of life.… So death is nothing to us; since when we exist, death is not yet present, and when death is present, then we do not exist. Therefore, it is relevant neither to the living nor to the dead, since it does not affect the former, and the latter do not exist.

According to Epicurus the fear of death is irrational, and in this brief passage he gives various reasons for thinking so. One reason is: what you do not experience as

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[15] But cf. Post's example of Mrs. S who agrees to cohabit with Mr. R falsely believing him to be her husband of 40 years marriage (Post 1995).

good or bad cannot be good or bad for you. But once you are dead, you do not experience anything anymore, so it cannot be good or bad for you to be dead. A second reason is as follows: *for whom* would it be an evil to be dead? It cannot be an evil for you while you live, and once you are dead you do not exist any longer, so then it does not bother you either. Therefore, there is never a subject that actually has the bad luck.

On first sight these are strong points, but the conclusion cannot be true. If it were true, you would not harm anyone by killing them, as long as you do so unexpectedly and without causing pain. *Of course* death is an evil for almost everybody. But Epicurus does force us to wonder *why* exactly this is the case.

As early as Antiquity the following objection has been raised against Epicurus. He is right when he says that death is not a positive evil, it is not a terrible situation to be in, because it is not a situation in which you can be at all. But that does not mean that death may not be a negative evil, an evil that consists of what you are deprived of. This *pure deprivation account*, by now the standard refutation of the Epicurean argument,[16] claims to be correct irrespective of the notion that one has of the value of life, so even if one grants Epicurus (or rather modern Epicureans) that that value consists of the sum total of the positive and negative experiences one gradually gathers.[17]

But Epicurus could still ask: who is really *affected* by that deprivation? Suppose you compare two possible lives: a shorter life which leads to death in 2020 and a longer life which ends in 2050. In that case, it is only a bookkeeping truth that the longer life until 2050 will probably consist of a greater sum total of positive rather than negative experiences than the shorter life until 2020. There is no moment in time, if the shorter life is yours, that this can make any difference to you. Both lives are completely identical until 2020, hence up to 2020 the deficit cannot make any difference to the value of your life. But after 2020 there are no longer two lives to compare with each other. You cannot be worse for no longer existing, as you cannot be worse for never existing.

How can the evil of death be explained then? Let me give two examples of people who really are deprived of something when they die. The first example, a variant on a story told by David Velleman, concerns a woman who is seriously ill during her youth, and long after that is still affected by it (Velleman 1991). Moreover, she grows up in a situation of social-economic deprivation. Furthermore, during her study she has to take care of a disabled parent, even while not completely cured herself yet, and she has to accept a boring job to provide for her cost of living. She succeeds in finishing medical school only with the help of enormous will power and extraordinary talent, but the day before she will receive her master's

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[16] Apparently also subscribed to by Dworkin (1993, pp. 229–231).

[17] McMahan (2002, pp. 496ff) accepts the deprivation account and therefore agrees that the Alzheimer patient has experiential interests in survival. That patient may also, as testified by his living will, still have critical interests in non-survival, but because the psychological continuity between his last and his present self is extremely reduced, on McMahan's view of prudential concern, these interests should be radically discounted. See footnote 34.

degree in medicine she dies as the result of a traffic accident. The second example is about a relationship in which both partners are continuously in conflict with each other so that every month they are about to break off the relationship while nevertheless staying together because they mean so much to each other. Some dramatic experiences bring them closer together and finally they feel not only a strong attachment but also an increasing harmony between them. Exactly at that point one of the two dies. That is, I would say, just as awful for both of them, not only for the surviving partner. In both cases there is a stage with a lot of sadness which seems to usher in a period that is happy and successful. That this development is interrupted is a loss as such, but it moreover deprives that first stage of its positive meaning, retrospectively: this preparatory stage has then been leading to nothing.

From an Epicurean point of view the value of each moment of life is independent of the value of each other moment, and the value of life as a whole is the sum of those discrete units. That is why it does not really matter that you are deprived of some experiences when you are no longer there to experience them. In my examples it is the other way around: the value of each moment depends on the value of a whole life or of a certain stage of that life, and that value is based on the structure or pattern that is being realized in that life. That structure may take on the shape of the execution of a plan, as in my first example: the meaning of each step is then based on the attainment of the final result. When the building collapses, its construction has made no sense. But the structure of life may also be more like a plot than a plan, as in my second example.[18]

A plan presupposes someone who makes a plan, and that must necessarily be someone who can place his present actions into a continuous line of actions and events from yesterday to tomorrow. A plot presupposes a main character who can put today's experiences into a continuum of experiences from yesterday to tomorrow. We must therefore object as follows to Epicurus' first argument: good and bad not only consist of single experiences, but also of the achievement of a certain life structure, of which death may be a radical interruption. We must answer the question which he formulates in his second objection as follows: the subject of the evil, the one suffering the evil, is the main character of the life story which has thus been interrupted.[19]

This latter answer could be objected to by saying that it seems to imply a form of backward causation which is usually held to be impossible. The key to a clear understanding here lies in the theory of action. Actions have a teleological structure, an

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[18] It is worth noting that Epicurus himself basically understood the value of a life in a structural way, as a quest for *ataraxia*. For that reason he could found a school and even leave a will, actions for which Cicero already accused him of inconsistency.

[19] As will become clear in Sect. 10.4, I do not wish to make very strong claims as regards these 'structural elements', as narrativists sometimes are tempted to do. I certainly do not presuppose "a self that is steadfastly committed to a stable set of identity-defining values and convictions, a self that expresses continuity over time, a self that is separate from all other selves and that essentially decides alone", as Koppelman (2002) describes the view she opposes. For discussion see also Delaere (2010, ch.2).

action is designed to bring about a situation which only obtains as a result of and therefore after the action. Therefore the success of that action can only be judged afterwards. No reverse causality is involved: the facts themselves are not determined retroactively, only the meaning and the value of those facts. An action may of course be valuable as such, even if it is not successful. But it is also possible that only useless expenses have been incurred when it fails to achieve its object.

But Alzheimer's patients in the penultimate stage no longer carry out any plans and do not live a life story any more. They can no longer align their present actions and experiences with those of the previous and next years, not even with yesterday's and tomorrow's actions and experiences. Because of that they can no longer deliberate about their actions, and because they have lost their sense of agency, not even really act anymore. They cannot engage in meaningful relations with others, because these presuppose a sense of reciprocity (Harvey 2006). They can only have pleasant and unpleasant experiences which do not add up in any meaningful way (McMahan 2002, p. 503). So the point Epicurus made *does* apply to such patients. For them death is no longer an evil. Only suffering is.

I have carried that advance directive with me half my life, and everyone who knows me can witness that my feelings about it never have changed. It is of vital interest to me that I need not go through that last stage, that I do not have to live on like that in the memories of my grandchildren. That is not the interest of my earlier self, my self in 1980 or in 2011, it is the interest of myself as such, as the main character of my life story from the beginning to the end, whether or not I am still aware of it. And during that last stage I will not have a conflicting different interest.

Suppose that during that last stage the unrest and confusion are gone and I just doze off in the sunshine and watch the Teletubbies. Is it, then, not in my interest to have a few more of those peaceful days? Following Bernard Williams we can make a distinction between conditional and categorical interests (Williams 1973). If I do get some extra days, then I would prefer them to be calm and pleasant: that is a conditional interest. It is no reason for wanting more extra days. In both my examples the main characters have an interest in the success of their enterprise or the development of their relationship, and that interest can only be realized if they are given time to live on. These are categorical interests. The personal value or disvalue of the life of the Alzheimer patient has to be decided in terms of his categorical interests, and these can only be determined from the views about his life as a whole which he had when he was still capable of having them.[20]

If we reject the pure deprivation account of the value of survival, we must conclude that you cannot have a purely experiential interest in survival. If it can be concluded from your living will that it is your critical interest to avoid that final stage of decay and devastation, that critical interest is therefore unopposed.

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[20] "…to affirm that severely demented patients retain an interest in experiencing simple pleasures while alive is quite different from saying that these patients retain an interest in being kept alive, so as to experience whatever pleasures are available to them" (Brock 1988, p. 90). Kuhse (1999) makes the same point. But most of the literature simply presupposes that it is a matter of showing compassion to the pleasantly demented to allow her to live, see e.g. Kadish (1992).

10.4 The Threatened Self

But this conclusion only applies to a late stage in the development of Alzheimer. Before that stage has been reached, the patient still has traces of critical interests on which he presently acts. He may be involved in some elementary project which he is able at least intermittently to recognize as such. Or he may interact with other people in ways which justify us to conclude that he cares for those people and to some extent responds to their responses, and therefore to ascribe to him an ongoing relationship with them. In such cases, it seems that he has a categorical interest in survival, because it is a precondition for going on with his project or his relationships.

Until that very last stage Alzheimer's patients still have a sense of self and concerns for that self. But you can only have a sense of self if you have some conception of the permanency of that self as existing through time. That is even shown when the patient like my mother-in-law wants to return to her familial home: she still identifies herself as the child of her parents. It is also shown when patients express their resentment for being treated in a way they feel to be humiliating, that very basic human concern for being properly respected (Sabat and Harré 1992; Sabat 1998; Jaworska 1999, 2007; Shiffrin 2004).

Hence it is still true of her that the value of each moment of her life depends on some rudimentary structure exhibited by that life through time. She may have lost the grasp on her life as a whole, or perhaps even on any significant stretch of it which includes the present. But she still has a conception of herself, and that may be enough to ascribe to her some interest in survival. Relatives may, for example, be touched by some characteristic way of responding to circumstances, a trace of humor, an act of gentleness. One structural element which binds the stages of our life together, in addition to our projects and ongoing intimate relations, is our characteristic way of coping with the vicissitudes of life, and it could therefore be suggested that it adds to the value of her life if that character is still expressed in some recognizable form under such adverse conditions.

In recent years laudable efforts have been made to get access to the inner life and in particular the remaining sense of self and agency of demented patients (Post 1995, 2000; Kitwood 1997; Sabat 1998; Cheston and Bender 1999; Nolan et al. 2002; MacQuarrie 2005; Hertogh et al. 2007). But what this new psychology of dementia has revealed to us, is fairly alarming.[21] Yes, there is a remaining sense of self, but it is not an intact sense of an intact self, and it is precisely for that reason that the descent into the abyss normally involves severe suffering. Being to some extent aware of the progressive loss of one's powers -a source of never-ending grief-, not being able to take care of oneself, feeling frightened because of events one cannot

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[21] For example, MacQuarrie (2005, p. 434), lists "annoyance, anger, hurt, shock, sadness, and exasperation" as the common emotional responses of Alzheimer patients to their situation; cf. the list in Kitwood (1997, p. 78). Because these emotions to some extent are adequate responses, they should not simply be considered symptoms to be treated, e.g. by anti-depressants.

understand, judging social situations incorrectly and then interpreting, sometimes correctly, other people's responses as disrespectful, panicking about events which don't happen, embarrassment, sadness and paranoia, all these states of consciousness reflect a sense of self, indeed, but a sense of a progressively threatened and disintegrating self. The increasing losses of cognitive ability leave a self which is confused and disoriented in the world, unable to execute any effective control, and to the extent that it is aware of its condition, feeling uprooted and insecure, lacking basic trust. Hence it is a mistake to suggest that an advance directive expresses an overrating of rationality and other cognitive performances at the expense of the affective dimensions of human life, which are sufficient to make it worthwhile. Basic cognitive abilities are our primary instruments of coping with the normal tasks of life, and therefore losing them can hardly fail to be experienced with extreme distress and alarm, even if it happens with only some dim awareness of the fact. It is also a mistake that the condition of dementia by itself doesn't cause extreme suffering. The physical symptoms may be relatively mild (although physicians often fail to recognize them because of communication problems). But, as Eric Cassell has taught us, pain, cramps, contractures, and other such symptoms only constitute suffering because of the attack on the self which they imply (Cassell 1991). To the extent that the demented patient has a sense of self which is still in some contact with reality, that self is and only can be a self under attack. Contrary to received opinion,[22] agitation, confusion, delusion and anxiety are therefore to be understood as essentially resulting from the dementia itself, and not from concomitant disorders (Post 1995).

It is therefore true that the demented self has still (contemporaneous) critical interests at a later time than Dworkin may have presupposed, but to the extent that the person can still assess her condition, this will only deepen her sense of loss.

It is only to be expected that the self defends itself by destroying its contact with reality, even beyond the extent to which this is already been done by its cognitive losses. Cees Hertogh has stated this well: the patient

> has to find a way of shutting out what happens to him, even if this means losing contact with reality, or he has to face the changes which occur, but this amounts to an apprehension, probably too painful to bear, that one is on the brink of losing oneself. (Quoted from Hertogh 2006; cf. Hertogh et al. 2007, p. 53)[23]

But then Hertogh cannot be right when he also holds that advance directives lose their authority because Alzheimer patients, like patients suffering from other fatal illnesses like cancer, adapt their preferences to their conditions. When they arrive in the state they abhorred, they find it not so bad as they feared. They are pushing back their frontiers (Hertogh 2008; Hertogh et al. 2007; cf. Dresser 2003). This analogy fails for two reasons. On the one hand Alzheimer patients do not, like cancer patients,

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[22] As represented by the three Dutch documents referred to in Sect. 10.2. Research by Rurup et al. (2005, cf. Rurup et al. 2010), however, shows that according to most nursing home doctors the suffering of demented patients can be unbearable, even in the absence of a concomitant illness.

[23] For a more general analysis of denial, including so-called anosognosia, as a coping strategy see MacQuarrie (2005).

arrive at a new assessment, taking into account new experiences, they progressively lose their capacity to assess. At the time at which their new condition would most likely lead them to change their mind, they may not have enough mind left to call it ‘changed’. But, secondly, whatever assessment they still make may itself be an expression of a fear too large to be faced, in particular with the coping resources still at their disposal. The only possible way of coping left is denial.[24]

But shouldn’t we even take them seriously in this state of denial? A critical interest, as Dworkin rightly stresses, is an interest in things happening, not only in experiencing them to happen. Your critical interests are not fulfilled when you are only given the impression of being respected or of being praised for doing something worthwhile.[25] Any interests satisfied in that case are only experiential ones. Similar your ‘critical interest’ in safely returning to the home of your parents cannot be fulfilled when they have been dead for many years. To the extent that the demented person has a wish to continue living, this cannot itself be seen as an expression of her critical interests, because it results from losing contact with reality.

As long as the demented patient still has a sense of self, and therefore a life which possibly might be sufficiently structured to sustain an interest in survival, that self will tend to be threatened to such an extent that his life will be characterised by continuous severe suffering. If the patient succeeds in avoiding this suffering, he can only do so by retreating into Meulenberg’s world of unreflected pains and pleasures.[26] Only in the first case he may still have categorical critical interests, but on balance these can hardly be interests in survival.

10.5 The Possibility of Conflicting Wills

In the last two sections I have discussed the possibility of a conflict between the earlier and later self, considering this conflict as a conflict of interests. However, it could also be a conflict of wills. The authors who use the conflict model often assume without any further analysis that patients suffering from Alzheimer’s normally choose life and resist death, as requested in their advance directive, when their disease has made considerable progress. The ambiguous terminology

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[24] The analysis is also inconsistent with the view that the suffering of Alzheimer patients is largely the result of ‘malignant social psychology’ (Kitwood 1990). For example, the restrictions on their freedom which Alzheimer patients understandably resent, are often necessary in order to prevent unacceptable risks to others. To the (considerable) extent that this view really *is* true, moreover, it only highlights the frailty of agency which to that extent is dependent on the good will of others.

[25] I do not deny that the beliefs and emotions of an Alzheimer patient may still match reality. But if they do, this will largely be a matter of accident. Sabat gives his professor to some extent a deserved sense of self-respect by including him in his research on the inner life of Alzheimer patients (Sabat 1998). But the professor would have the same feelings if no such research was actually going on.

[26] As a result either of the psychological mechanism, described by Hertogh, or simply of the progressive loss of his mental faculties.

is sometimes used that “they no longer want to die”. The phrase suggests that something is present: the will not to die, though it only asserts that something is absent: the will to die.

A recent paper deduces the will not to die from the fact that patients accept the care offered to them (Hertogh et al. 2007). But if patients have the conditional wish to be well taken care of while they live, it does not follow that they also have the categorical wish to continue to live. Only if the care offered to them is solely aimed at prolonging life, one could in principle decide, on the basis of the acceptance of the offer, that patients have a wish to stay alive. However, that presupposes a correct understanding of the meaning of the offer. It is doubtful whether Alzheimer patients understand that meaning, even when they are given explicit information about it.

During the development of Alzheimer’s there is a moment when the patient can apparently still experience something – he reacts to pain stimuli, for example – but no longer want something. An act can only be said to be willed if the acting person understands that the act contributes to a result that she desires.[27] That presupposes the ability to have preferences for possible situations and an elementary understanding of cause and effect. Of course we do all sorts of things without thinking about causality and it is not even necessary for us to be able to explain causal relations in language. However, if these are the only ‘acts’ we perform, at a certain moment it becomes likely that the acts are only mechanical reactions to stimuli. That we still want something only appears from non-standard situations, when we think of a relatively new way to satisfy a wish. People who care for demented patients often and understandably tend to give an ‘anthropomorphic’ interpretation to completely automatic behaviour. They thus sometimes deduce a ‘rejection of food’ from a negative reaction to food being offered or from pulling out a tube.

If a will no longer exists, neither does a will to live on, so much is clear. However, the opposite is not true. It is quite possible that the patient suffering from Alzheimer’s still wants all sorts of things, and may even *say* that he does not want to die, while not really knowing what it is that he says he wants. It has to my knowledge not been studied to what extent Alzheimer’s patients still have a grasp on the concept of death, but it has been studied in the case of children (Carey 1985). It turns out that children until the age of three cannot distinguish between living and non-living objects. Until the age of about five they see death as a sort of sleep from which you can wake up at any moment. Only after that do they understand that death is final, but not yet that this is associated with the termination of vital functions. It is therefore a cognitively complicated task to understand that something that exists may cease to exist, that this also goes for living beings, human beings, and even yourself.

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[27] It is therefore mistaken to think that we do not and cannot know whether a patient in an advanced state of Alzheimer’s still sticks to her request (Dresser 1995; Harvey 2006; Gastmans and De Lepeleire 2010). If the counterfactual question is asked: what would the person have chosen if he had still been able to choose anything, we should observe that the answer is irrelevant, because in that case she would not be in the condition for which her living will has been made.

When someone is capable of willing something, that does not mean that he is competent to determine his will. The ability to evaluate and the ability to deliberate are crucial to this ability. These two abilities are interrelated: an evaluation is distinguished from mere preference, or even from a characteristic pattern of preference, because it is a judgement with a pretension to truth, a judgement which may be the object of reflection and discussion. Hence someone can only be competent if he has a minimal insight into the alternatives among which he can choose and into the consequences of his choices for the realization of his values. There is a time during the development of Alzheimer's when the patient may still be able to want something, but is not able to evaluate, to deliberate and to communicate about her values and choices.

Prior to this, there is a phase in which those general capabilities are not fully absent but when we nevertheless cannot regard the patient as competent to make a decision about life and death, because she cannot assess the particular alternatives from which she must choose and their consequences. Let us assume that the patient at this stage still has a sufficiently adequate concept of death. Then, and only then, a conflict may arise between the advance directive and the actual will of the later patient.

Authors who defend the authority of the living will, such as Ronald Dworkin, have a ready solution to that conflict: an incompetent decision does not count. In response various authors have tried to extend the concept of competence in such a way that it can still be attributed to patients suffering from Alzheimer's in rather advanced stages of the disease (Jaworska 1999; Shiffrin 2004).[28] This fits in with a general trend in the literature about our interaction with people having serious cognitive defects. It is clearly the result of the special prominence that the principle of respect for autonomy has received in medical ethics: in order to be able to take into account the will of people with serious cognitive defects we must first attribute competence to them.

I have problems with both positions. If, as Hertogh's observation suggested, the rejection of the living will's provisions results from a denial of the truth because it is too horrible to be faced, this rejection cannot be understood as being made competently, whatever the general abilities of the patient. On the other hand, the starting point that Dworkin and (most of) his critics share – that decisions do not count at all, if they are made incompetently – seems also false to me. To begin with, I don't think that there is a very clear borderline on the scale of the relevant abilities between the competent and the incompetent, which can justify treating them in completely different ways (Arneson 2005). But moreover, we should not simply disregard the will of clearly incompetent people, for example young children. Not only competent people value taking charge of their own lives and feel slighted by paternalism.[29] We should

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[28] It is interesting that Jaworska (2007) does not analogously claim that the capacity for caring which she ascribes to patients in an advanced stage of Alzheimer amounts to a capacity for autonomy. But she does argue that such cares, as those of small children, should be taken into consideration.

[29] Shiffrin (2004, pp. 203ff) and Jaworska (2007) are fully aware of this, as is Kadish (1992, p. 874).

certainly do so as long as meeting that will does not impose unreasonable demands on others, and does not conflict with the interests of the person in question. The question whether someone is competent is only asked in practice when the latter is the case. Even when there is a conflict between will and interest, it may sometimes be justified to decide in favour of the will of the incompetent person. This may be a matter of respect, but it may also be instigated by the wish to maintain a good relationship with her.

I have no general view about the solution of this conflict in the case of a negative living will. Much depends on a sympathetic understanding of the extent of the patient's suffering. Because doctors are liable to err at the side of rejecting the directive, it may be all to the good that the law provides a counterbalance to this, in particular when the courts do not blindly enforce the law.[30] As for a positive request for euthanasia, it seems unthinkable to me to actively put an end to the life of a patient who knowingly resists, even though the situation is so dramatic that we would be prepared to consider it in a patient who can no longer express his will and even though the patient has completely erroneous ideas about his circumstances and prospects.

10.6 What Should the Doctor Do with My Negative Will?

When the person is still trying to adjust to her new condition, this is normally an extremely painful process which fully warrants a precedent wish to avoid it. The objection made to the view that an Alzheimer patient only has experiential interests is that his life story goes on, and this is true, but it is normally a tragedy. The authors who have so much contributed to our new understanding of the Alzheimer patient as a person, have also, mostly contrary to their own intentions, deepened our appreciation of the possible appropriateness of the living will. Precisely the appeal to take the patient's perspective seriously should make us sensitive to the extent to which the deteriorating condition of the Alzheimer patient involves unbearable suffering.[31]

It is a blessing when eventually "all the confusion, embarrassment and agony of self-observation are forfeited in favour of grateful amnesia" (Post 1995). To that

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[30] Maclean (2008) shows that British courts tend to countenance a physician's rejection of a living will when the physician appeals to the best interests of the patient. On his view this tendency undermines the Mental Capacity Act 2005, because he interprets that law as exclusively aiming at promoting respect for autonomy. Dutch law explicitly permits the doctor to depart from the directive for "well-founded reasons", but this should not be taken to mean that the doctor can simply act on his own judgement of the patient's best interests. Perhaps the British law should be interpreted in a similar way, as giving the living will a limited authority.

[31] Goering (2007). Hertogh et al. (2008) concede in their reply that "he has a point", but then go on to ask whether it is not too much to ask of a doctor to kill such a patient. Perhaps it is, but the reason cannot then be provided by the interests of the patient, see Sect. 10.7.

extent Meulenberg's comment on Iris Murdoch which I quoted in my introduction was to the point. But it is by itself a fully understandable wish to avoid that stage as well, and that wish is again unopposed by any interest of the demented individual in survival.

So do I think that the doctor who treats me must simply carry out my advance directive when the time is there? Certainly the first stipulation, on abstention from treatment. Of course, people change their view of life, sometimes dramatically, while they live and it would be ridiculous to put claims on Paul's life deriving from the value system of Saul. That would indeed be a form of "self-paternalism", of domination of the earlier over the later self.[32] Saul's values are no longer valid for determining Paul's interests, because they have been *revoked.* But the development of dementia is not a process of conversion. If I find myself in the situation that I describe in my advance directive, I have not revoked the values expressed in that directive, they have only disappeared beyond the horizon. That is why those values are still in place for the evaluation of what my life means to me, even though I can no longer perform that evaluation myself. Otherwise you could have no reason either to honour after my death my wishes concerning my estate, my body, my sperm or my organs.[33] The interests expressed in my living will are my categorical critical interests, and will be so at the last stage of dementia as much as they have ever been.[34]

Even if I have subscribed to those values all my life, couldn't I be mistaken about them? That is possible but irrelevant. If my doctor, or even my family, disagrees with me, either about my values or about my beliefs, for example my rejection of the pure deprivation account of the evil of death, why should my fate depend on their views?[35] If, on the other hand, Frans Meulenberg draws up an advance

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[32] My view is that the interests of a past self do not only count for less than the interests of the present self, as Jaworska (2007) proposes. Rather, as such they count for nothing. In Parfit's famous example of the Russian count the dilemma for the count's wife is only created by her promise to disregard his present preferences, not by his former preferences as such. Similarly, if we frustrate a child's present desires in order to protect his future flourishing, we do not solve a conflict of interests between stages of the self in favour of the future self either, because the child already has an interest in his future condition. The concept of 'interest' is backwards transitive. I therefore agree with Dworkin (2004, p. 367), when he comments that both Shiffrin and Jaworska do not really accept that the child, the adult and the Alzheimer patient are one and the same person.

[33] The denial of the possibility of posthumous interests often rests on the mistaken idea that they would involve some kind of reverse causality, see Sect. 10.3.

[34] McMahan (2002) denies this, see footnote 17. But he then goes on to claim that the value of the coherent character of my life as a whole should still override these interests. But if that value is not a personal value to me, as I will be at that time, it can only be either an impersonal value, or a personal value to my irrevocably past self. On neither interpretation this seems sufficient to justify killing someone.

[35] Blustein (1999), Koppelman (2002) and Nys (2012, this collection) advocate leaving the decision to arbitrate between the former and the later self to surrogates, significant others who have co-authored and therefore are still able to continue authoring the story of my life. Perhaps that is wise counsel, but, as Nys recognizes, that doesn't mean that these surrogates have any *authority* to decide unless I have given it to them.

directives requiring all life-prolonging measures in the case he is pleasantly demented, why should it be relevant that his doctor or his family agrees with Epicurus and me? Both his and my advance directive is not only a document which informs you about our point of view as regards our life and its stages, and thus enables you to form your own idea about our categorical interests. It is also a public act by which we authoritatively determine the normative position of any doctor who considers treating me. That the determination is authoritative means that it's validity does not depend on an assessment of its content.[36] I would claim that this content-independence even covers the philosophical issues I have discussed. Even if I am mistaken in my view that one cannot have a merely experiential interest in survival, that doesn't justify a doctor to put my living will aside in order to give me some additional happy days. Doctors are only on the scene because of their medical expertise, not because they have any special competence in determining people's basic interests as regards life and death. That is one reason not to entrust them with the authority to determine those interests. Note that this reason does not derive from the value of autonomy.[37]

The only possible exception to the authority of a negative living will is the situation in which the person involved, although incompetent, expressly states that she does not want to die, while also understanding to some significant extent what it is she does not want. In this single case there is a conflict of wills between an earlier and a later self. And in that case, I have suggested, there may sometimes be some reason for doubt about the binding nature of the directive. For in this case it is in some sense correct that the earlier self imposes itself on the later self. It is true: not from aggression but from justified compassion evoked by the present self,[38] hence not as a tyrant, but still in a paternalistic fashion. And in this particular case such 'self-paternalism' is not absolutely justified by the fact of incompetence.

10.7 What Should the Doctor Do with My Positive Will?

But what about the second stipulation, about the active ending of my life? That is a more complex question. For there is something inherently problematic about ending life, even about putting an end to the life of a person who wants to die and has a fundamental interest in dying.

Almost all doctors feel that way, even when euthanasia is requested by a patient who is beyond doubt suffering unbearably. As a result they don't consider

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[36] As observed in footnote 3 most Dutch physicians only accept the living will as a source of relevant information, not as a binding document.

[37] Authors who believe that recognizing the authority of advance directives amounts to overrating this value (see Sect. 10.2) fail to properly distinguish between the value of and the right to autonomy, cf. Feinberg (1986, ch. 18). The right may protect the value, but it can also be founded on many other considerations (den Hartogh 2000).

[38] Cf. footnote 7 (Kadish 1992, p. 871; Koppelman 2002, p. 75).

the situation as providing a ‘medical exception’ to the prohibition on killing, but rather as a conflict of duties, even though the duty to prevent further suffering may ultimately tip the balance.[39] They are conscious of a duty not to kill which is not a duty which is owed to the patient. That compassion sometimes prevails may only be possible because severe suffering evokes that emotion directly and urgently, and even in that case only when they can share responsibility for acting on it with the living person herself, not only with a piece of paper.[40] But to sneak up with a deadly needle on that Govert den Hartogh who is dozing off in the sunshine is a different matter altogether. Even if you agree about his interest, it is a fairly abstract interest. And he might just as soon develop a pneumonia.

It is an important question for ethics whether the psychological obstacles to killing which doctors experience are just that, an atavistic remainder of an old taboo, or have moral meaning, and if so, why.[41] Let me only observe for now that it is just as well, particularly in a country where euthanasia is allowed (on strict conditions), that it is psychologically difficult for doctors to go about ending people’s lives. I should be lucky if at the appropriate time I could find a doctor (you keep your hopes up) willing to honour my positive advance directive, but, speaking amongst ourselves, I would not entirely trust that same doctor in other circumstances.

So I do understand that I cannot simply expect doctors to fulfil my wish; in particular I understand that it is difficult for them to do so without my continuing cooperation. But they should not say that they refuse to do so because of *me,* in my interest, out of respect and consideration for the person that I am or have become. According to Cees Hertogh even in the most severe cases of suffering “what holds us back is the defenceless power of human need and vulnerability.”[42] (Hertogh et al. 2006) That is extremely paradoxical: is it my very vulnerability to extreme suffering which prevents you from showing mercy?

If doctors say that they hold back because they care for me, they are both deceiving themselves and disrespecting me. That is what I would like to instill in them. And that is why I go on carrying that living will with me.

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[39] It may be no more than an accident of history that the Dutch euthanasia law is basically founded on this idea of a conflict of duties, but this foundation at least reflects doctors’ feelings, and may well be the appropriate moral framework for evaluating physician-assisted death.

[40] Most of the family doctors interviewed by Rurup could imagine executing the positive request of the living will, but only if these two conditions had been fulfilled (Rurup et al. 2010; cf. van Delden et al. 2011, pp. 157–159).

[41] The question requires a more extensive discussion which until now I have only provided in Dutch (den Hartogh 2009).

[42] Cf. footnote 31. He also states that such extreme suffering is not “unbearable” in the sense of the Dutch euthanasia law because this notion requires doctor and patient to agree about the unbearableness (Cf. van Delden 2004). Both van Delden and he note that on this interpretation the law is incoherent, because the request of a living will which the law recognizes as authoritative, can then never be granted. To me that rather seems a decisive reason to reject this interpretation of the law.

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