

## **Euthanasia and dementia**

Handling advance directives in the light of the someone else problem

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## **Abstract**

In this thesis I'll focus on the handling of advance euthanasia directives and consider if it is morally acceptable to euthanize patients suffering from dementia based on an advance directive in the light of the someone else problem. This problem will have a prominent role throughout this research for it is feared that patients completely change into someone else due to the radical psychological change they undergo in the context of dementia and it is deemed to be unacceptable that the request of one person would lead to the death of another. An overview of the current practice, in which legal regulations, the physician's and patient's perspectives are discussed, will be provided. Hereafter the someone else problem is approached from the theoretical perspectives of the psychological, biological and narrative approaches of personal identity.

Even though a charitable interpretation of the psychological approach will expose a fracture in persistence of personal identity over time, this approach will turn out to rest on a faulty conception of the human essence and the biological approach will restore continued existence over time. But despite numerical continuity of persons as biological beings, the narrative approach of personal identity will expose the qualitative changes that patients undergo due to their suffering from dementia. Hereto I'll consider whether an appeal to precedent autonomy can resolve the handling of advance directives in the context of narrative identity. It will however become evident that patients remain to possess a degree of autonomy in the initial stages of their disease and can hold values throughout the development of their illness despite their qualitatively changed identity. Hereto I'll conclude that the someone else problem does impede the euthanizing of demented patients based on an advance directive and that one can only adhere to one's predetermined directive if this is not in conflict with one's current values and if one's final degree of autonomy, and thus his capacity to value, has disappeared completely.

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## Introduction

*Woedend staar ik de voorkamer in. Alsof ik woorden verlies zoals een ander bloed. En dan opeens ben ik weer vreselijk bang. De aanwezigheid van alles! Ieder voorwerp lijkt me zwaarder en solider dan het hoort te zijn (misschien omdat ik er een fractie lang de naam niet meer van weet). Ik ga vlug op de bank liggen en sluit mijn ogen. Een soort zeeziekte in mijn denken lijkt het wel. Onder dit leven woelt een ander waar alle tijden, namen en plaatsen door elkaar heen spelen en waarin ik als persoon niet meer besta.<sup>1</sup>*

This short fragment from the Dutch novel *Hersenschimmen* pictures the gradual loss of memory that is caused by dementia, in this case from the perspective of the 71-year-old Maarten Klein. At first, readers are confronted with what seems to be harmless erring, but this slowly takes on dramatic proportions; Maarten loses self-control, he is unable to discern between reality, fantasy and memory. His perceptions and thoughts become more and more fragmentary throughout the book and he slowly and inevitably loses grip on his life, until all that is essentially left of him are figments of mind.

This perspective on dementia emphasizes the possible suffering that this syndrome entails. I explicitly choose to denote this as a syndrome because dementia does not concern a single disease in general but multiple diseases, which I will describe in more detail later on. This also indicates that dementia has different effects, not only depending on the specific cause of the disease but also depending on different phases the disease entails and the effect the disease has on a specific individual. Despite the similar inherent outcome of mental deterioration and the increasingly frequent occurrence of the most common forms of dementia at older age this doesn't imply that dementia necessarily brings about severe suffering in the last phase of life, as was depicted in *Hersenschimmen*. Nevertheless it seems as if this specter of dementia looms in the minds of many people who fear the process of deterioration of personality, functions and skills that will eventually lead to total loss of the self and dependency on others before death, and wish to be spared to undergo this progressive syndrome. In order to avoid such future suffering some people choose to compose an advance euthanasia directive as a precautionary measure. This directive contains the most definite choice one could ever make in a lifetime, a request for active life-ending<sup>2</sup>. The value that can be attached to such a directive nevertheless seems to be highly controversial and is currently heavily debated, not only by medical professionals and ethicists but also in the public debate.

In line with the new law on euthanasia, which was enforced in 2002, the legal regulations concerning euthanasia in The Netherlands seem to be rather liberal. Euthanasia is not constituted as an offence if it is carried out by physicians and if they are able to fulfill the criteria of due care. Advance directives also have a legal status, these directives are taken to be living wills in which a competent

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<sup>1</sup> J. Bernlef. *Hersenschimmen*. Groningen : Wolters-Noordhoff, 1984. p. 65.

<sup>2</sup> Euthanasia, in which death is brought about by an act of a physician – he administers the drugs directly to the patient by injection or intravenous – at the explicit request of his patient, is sometimes mistaken with but differs from 1) assisted suicide, in this case the physician provides the drug to the patient but the patient takes it independently (however, just like the practice of euthanasia this practice falls under the Termination of life on request and assisted suicide (review procedures) act) ; 2) the passive omission of death by withholding or withdrawing of treatment, either at the initiative of the patient or the physician; and 3) palliative care which is intended to relieve a patient's suffering in the last phase (more precisely: two weeks) of his life.

person requests or rejects a certain type of medical treatment, and in this context this particularly concerns a wish for euthanasia.

The variety of values that are being ascribed to these directives leads to a problematic opposition. According to many the possession of an advance euthanasia directive is a sufficient condition for undergoing euthanasia, and many patients expect these to be grounds on which they should receive life-ending treatment. Patients who possess an advance euthanasia directive regularly take their directive to compensate the lack of future expression; for those who fear death won't come soon enough advance directives seem to be a way to secure future medical treatment that is in line with the values that have played a central and characteristic role throughout one's life. Physicians nevertheless generally approach these requests cautiously and hardly ever act on such a directive in practice; in 2012 only 42 patients who were suffering from dementia received euthanasia.<sup>3</sup> When physicians are requested to assist in fulfilling a death wish they regularly can't or won't perform euthanasia on demented patients, especially in cases of dementia in a late state, as will be explicated more thoroughly later on.

I take there to be several ways to challenge the authority of these directives. When focusing on the legal requirements of due care related to these directives it is for instance unclear if these can be met due to the impaired communication between physician and patient. When focusing more specifically on the requirements concerning the hopeless and unbearable character of suffering it is even challengeable if these can be met unambiguously at all. But above all, it is feared that dementia causes patients to change into completely different persons due to the radical psychological change they undergo, and that this change derogates the value of one's advance directive; this is what I'll refer to as 'the someone else problem' and this problem will play a central role throughout this writing.

In order to get a grip on the complex situation I will firstly sketch an overview of the current practice. Hereafter I'll consider whether and in what way the someone else problem forms a valid argument against euthanasia in this context, and in relation to this problem I'll consider the role of a patient's precedent autonomy in the handling of advance directives. The examination of these central issues will eventually enable me to provide an answer to the fundamental question:

Is it morally acceptable to euthanize patients suffering from dementia based on an advance directive in the light of the someone else problem?

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<sup>3</sup> Regionale toetsingscommissies euthanasie – Jaarverslag 2012 (via: [http://www.euthanasiecommissie.nl/Images/JV\\_RTE2012\\_WEB\\_DEF\\_tcm52-37320.pdf](http://www.euthanasiecommissie.nl/Images/JV_RTE2012_WEB_DEF_tcm52-37320.pdf), consulted on 04-04-2014), p. 64.

## 1. An overview of the current practice

Dementia is an unaccustomed ground for euthanasia. While patients expect their advance directive to warrant euthanasia, physicians generally don't act on this request. Nevertheless, it is not easy to provide an accurate description of the current practice and the debate concerning advance euthanasia directives because of the delicate nature of the subject and the variety of values that are being ascribed to these directives. Despite these difficulties I intend to provide an overview of the current practice of euthanasia based on advance directives in the context of dementia and the various statuses that are being ascribed to these directives from the perspective of the law, physicians and patients. I'm well aware that these are not unequivocal groups and that these groups don't necessarily consist of like-minded individuals as differences in opinion are not reserved to the distinct groups but might well exist within these groups. Despite its inevitable binary structure this description can be conceived as a general overview of the current situation.

### 1.1 Legal regulations

Despite the liberal character of the Dutch regulations concerning euthanasia it is a mistake to believe that the practice of euthanasia has been fully legalized; subsection one of article 293 of the Dutch Criminal Code expresses that one who intentionally ends the life of another on that person's explicit and earnest request shall be punished by imprisonment or a fine.<sup>4</sup> The practice of euthanasia is a criminal offence. It is only in subsection two of the same article that an exception is made concerning the role of physicians, special requirements under which fulfillment of the act by a physician is not constituted as an offence are expressed here.<sup>5</sup> The law explicitly allows for euthanasia to be carried out by physicians and provides a legal defense for them. It follows from this that a physician is obliged to report the termination of life to the municipal forensic pathologist.

Additionally, the physician is obliged to act in compliance with the criteria of due care as stated in subsection one of article two of the *WTL*<sup>6</sup>, which was enforced in 2002.<sup>7</sup> In line with these criteria of

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<sup>4</sup> Dutch Criminal Code – Article 293 (via:

[http://wetten.overheid.nl/BWBR0001854/TweedeBoek/TitelXIX/Artikel293/geldigheidsdatum\\_28-01-2014](http://wetten.overheid.nl/BWBR0001854/TweedeBoek/TitelXIX/Artikel293/geldigheidsdatum_28-01-2014), consulted on: 22-04-2014 .)

[Roughly translated: He who intentionally ends the life of another on that person's explicit and earnest request shall be punished by imprisonment (not exceeding twelve years) or a fine of the fifth category.]

<sup>5</sup> Dutch Criminal Code – Article 293 (consulted on: 22-04-2014.)

[Roughly translated: The fact that was described in the first section is not a criminal offence if it has been committed by a physician whose actions were in accordance with the requirements of due care, stipulated in article 2 of the law on reviewing the termination of life on request and assisted suicide and if this is reported to the municipal forensic pathologist in accordance with article 7, subsection 2 of the burial and cremation act.]

<sup>6</sup> *Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding/Termination of life on request and assisted suicide (review procedures) act*

<sup>7</sup> *WTL* – Article 2.1 (via: [http://wetten.overheid.nl/BWBR0012410/geldigheidsdatum\\_22-04-2014](http://wetten.overheid.nl/BWBR0012410/geldigheidsdatum_22-04-2014), consulted on: 22-04-2014). As translated by Jurriaan de Haan (in his 'The new Dutch law on Euthanasia', in: *Medical Law Review*, volume 10, 2002. pp. 57-57. Here: p. 62.):

"the physician has to convince the committee of the following six things:

- that he was satisfied that the patient has made a voluntary and well considered request for euthanasia;
- that he was convinced that the patient was suffering unbearably and hopelessly (i.e. there was no reasonable alternative in his situation);
- that he has informed the patient about his situation and the prospect of improvement;

due care the request for euthanasia must, above all, be voluntary. The patient ought not to be influenced by any external force and must possess the mental abilities to rightfully make the request; one must be competent to oversee the consequences and possible alternatives in order to make a voluntary request. This is linked to the demand for a well-considered judgment, for only a competent patient has the capacity to make the preceding careful and thorough consideration. Furthermore, the suffering a patient undergoes must be hopeless, with no prospect of improvement, and unbearable. Based on the medical diagnosis and prognosis the prospect of improvement can be determined reasonably objective; there is considered to be no prospect of improvement in suffering if the disease is incurable and if it is impossible to alleviate the symptoms to such an extent that it becomes bearable.<sup>8</sup> Identifying the (un)bearableness of a certain condition is nevertheless far more difficult, for the amount of pain or suffering one can bear differs from one person to another, not only due to the conditions one is in but also due to one's personal perspective on the situation. Additionally, before a physician can respond to a patient's request for euthanasia he must fully inform the patient about his current situation, the nature of his disease and the associated prospects. The patient also needs this extensive information in order to make a well-considered judgment, as has been described earlier. Eventually the physician and the patient have to make a joint decision; both of them have to be convinced that no other reasonable solution is at hand. In order to monitor this process it is required that at least one other independent SCEN<sup>9</sup>-physician, who has been trained to provide colleagues with professional and independent advice, gets to see the patient in question. It is not legally required that this second physician speaks with the patient, it is only obliged that he should see the patient. This consulting physician investigates if each of the above mentioned requirements of due care can be met. If this is the case a physician may grant his patient euthanasia and must carry it out with due medical care; drugs should be administered in a medically and technically correct way and a physician is obliged to carry out the act of euthanasia himself.<sup>10</sup>

In addition to this, and of crucial importance in the context of advance directives, Article 2.2 of the Dutch law on euthanasia describes the possibility of euthanasia for patients who are no longer able to competently express their request for life-ending:

If the patient of sixteen years of age or older is no longer able to express his wishes but previously had, before he found himself in this condition, a reasonable understanding of his interests in this situation, and possesses a written statement containing a request for euthanasia, a physician may give effect to this request. The requirements of due care, as stated in the first paragraph, still apply accordingly.<sup>11</sup>

Advance directives in which a competent person requests euthanasia have a legal status; it may replace the current request of an incompetent patient. It is important to note that there hasn't been made a legal differentiation between disorders in the context of these advance directives, the law is

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- that he had to come to the decision that the patient's suffering was hopeless together with the patient himself;
  - that he has consulted one other, independent doctor, and, finally,
  - that he has terminated the patient's life with due medical care and attention."

<sup>8</sup> 'B. Uitzichtloos en ondragelijk lijden' (via: <http://www.euthanasiecommissie.nl/zorgvuldigheidseisen/lijden/>, consulted on: 22-04-2014).

<sup>9</sup> *Steun en Consultatie bij Euthanasie in Nederland/Support and consultation for euthanasia in The Netherlands*

<sup>10</sup> 'F. Medisch zorgvuldige uitvoering' (via:

<http://www.euthanasiecommissie.nl/zorgvuldigheidseisen/uitvoering/>, consulted on: 22-04-2014).

<sup>11</sup> WTL – Article 2.2 (via: [http://wetten.overheid.nl/BWBR0012410/geldigheidsdatum\\_22-04-2014](http://wetten.overheid.nl/BWBR0012410/geldigheidsdatum_22-04-2014), consulted on: 22-04-2014).

intended for patients suffering from a terminal illness as well as patients who come to suffer from dementia. Moreover, the possibility of euthanasia is intended for all patients who suffer unbearably, as was emphasized by former minister of public health Els Borst<sup>12</sup>.

These advance directives do not have a universal form. For instance the NVVE<sup>13</sup> distributes advance directive documents to its members<sup>14</sup> in which they can confirm and supplement their wishes regarding euthanasia. But it is also allowed for patients to compose their own directive from scratch, sometimes these are even taken to have higher value because they have a more personal character. It's however not necessary, but more convenient for both the patient and the physician, especially in emergency situations, for a patient to express his advance directive in a written form; the KNMG<sup>15</sup> confirmed that an advance directive may also consist of clear reports of discussions with the patient, relatives and social workers and as long as a patient is competent a verbal statement suffices.<sup>16</sup>

It is the task of the Regional euthanasia review committees to assess whether physicians have rightfully complied with the lawful requirements in terminating the life of a patient, and if a physician is judged to have acted in a careless way the case is to be reviewed by the Public Prosecution Service. In 2012 a total of 4.188 cases of termination of life were reported to regional review committees, this consisted of 3.365 cases of euthanasia, 185 cases of physician assisted suicide and 38 combinations of euthanasia and physician assisted suicide.<sup>17</sup> The nature of the condition that gave rise to the termination of life was dementia in 42 of the cases.<sup>18</sup> This however only indicates that in 42 cases dementia has eventually led to the termination of life, the actual amount of requests for life-ending based on dementia is presumably higher. The committees judged the proceedings in two of these cases to be careless.<sup>19</sup> The first case concerned the termination of the life of a patient suffering from Huntington's disease and dementia who initially signed an advance directive but later on never affirmed the desire and even rejected euthanasia. As there was no clear and consistent picture of the patients' wish concerning euthanasia over the years, the review committee judged that the physician had not made clear that the patient experienced her suffering to be unbearable and that there were no other reasonable alternative solutions to the situation.<sup>20</sup> In the other case it was judged that the SCEN-physician took over too much of the tasks of the treating physician. As the treating physician had no experience with euthanasia, he turned to a SCEN-physician which he knew to have experience consulting demented patients. Even though this was intended as an extra precaution it was conceived to affect the required independence of the SCEN-physician and was thus eventually

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<sup>12</sup> Els Borst. 'Inleiding', in: *Wils verklaring*. Bilthoven : 2013 (via: <http://wils-verklaring.nl/inleiding-wils-verklaring-door-dr-els-borst-eilers/>, consulted on: 11-05-2014).

<sup>13</sup> *Nederlandse Vereniging voor een Vrijwillig Levenseinde /Right to Die-NL*

<sup>14</sup> An example of these directives (as well as their additional clause for dementia) has been attached to this thesis as appendix I (these documents were derived from: NVVE. *Toelichting bij de wilsverklaringen*. Amsterdam : 2013, 9<sup>th</sup> revised edition. pp. 28-30).

<sup>15</sup> *Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst/Royal Dutch Society for the Promotion of Medicine*

<sup>16</sup> 'Moet euthanasieverzoek schriftelijk gebeuren?' (via: <http://knmg.artsennet.nl/Diensten/artseninfolijn/FAQ-Praktijkdilemmas/Casus-Artseninfolijn/Moet-euthanasieverzoek-schriftelijk-begeuren.htm>, consulted on: 23-04-2014).

<sup>17</sup> Regionale toetsingscommissies euthanasie – Jaarverslag 2012, p. 64.

<sup>18</sup> Regionale toetsingscommissies euthanasie – Jaarverslag 2012, p. 64.

<sup>19</sup> Regionale toetsingscommissies euthanasie – Jaarverslag 2012, p. 17.

<sup>20</sup> 'Casus 3', in: *Regionale toetsingscommissies euthanasie – Jaarverslag 2012*. pp. 18-23.



reviewed as a careless act.<sup>21</sup> Another remarkable case, concerning a patient suffering from dementia in a late state, was judged to be careful. The patient had been diagnosed with dementia early in 2010, accompanied by paranoid delusions and hallucinations which caused much fear. Later on the porous structure of her bones led to many fractures which caused the patient to suffer from severe pain. She had already discussed euthanasia in general with her physician in 2004 and eventually handed her physician an advance euthanasia directive early in 2011. Throughout the progression of her disease she again referred to this wish and stated she wanted euthanasia in case her suffering became unbearable. Her children eventually requested to have her life terminated and the patient indirectly confirmed her wish “door uitspraken zoals: ‘dat zij zo niet langer wilde leven’, ‘dat zij het niet meer volhield’”. Tevens weigerde zij op een gegeven moment haar medicatie ‘omdat zij toch dood wilde’<sup>22</sup>. This, along with the other criteria of due care, eventually led the regional review committee to judge the physicians’ actions in this case to be careful.<sup>23</sup>

## 1.2 The physicians’ perspective

Numerous physicians have been or will be confronted with patients suffering from dementia. Currently around 1% of people over 65-years-old suffer from dementia, and as the number of elderly people in The Netherlands will increase substantially over the coming years it is estimated that about 412.000 patients will suffer from dementia in 2050.<sup>24</sup> Dementia has been denoted as a syndrome because it concerns multiple diseases, such as Alzheimer’s disease, vascular dementia, frontotemporal dementia and Lewy body dementia. Because Alzheimer’s disease is the most common form of dementia many people associate the symptoms of this disease with dementia in general: “geleidelijke progressieve kortetermijngeheugenstoornissen, gevolgd door langetermijngeheugenstoornissen, fatische stoornissen, apraxie, agnosie en stoornissen in de uitvoerende functies.”<sup>25</sup> Alzheimer’s disease is known to have a gradually progressive course, one out of seven patients eventually reaches the most severe vegetative state<sup>26</sup>, and this state of suffering is feared by many patients. The second most common form of dementia, vascular dementia, is caused by a disruption of the blood supply in the brains whereby brain tissue is damaged and dies. The symptoms of this disease vary depending on the area of the brain that is affected, but, in contrast with Alzheimer’s disease, the course of vascular dementia is much more cascading and symptoms can increase or decrease from day to day.<sup>27</sup> This latter disease does not necessarily involve constant progressive deterioration of mental capacities; symptoms can also decline in this case. The rate at which any of these diseases become more severe differs from person to person. Nevertheless a description of dementia in purely medical terms is not an adequate means of explicating the full

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<sup>21</sup> ‘Casus 12’, in: *Regionale toetsingscommissies euthanasie – Jaarverslag 2012*. pp. 47-49.

<sup>22</sup> ‘Casus 4’, in: *Regionale toetsingscommissies euthanasie – Jaarverslag 2012*. p. 24.

<sup>23</sup> ‘Casus 4’, in: *Regionale toetsingscommissies euthanasie – Jaarverslag 2012*. pp. 24-28.

<sup>24</sup> Health Council of the Netherlands. *Dementia*. The Hague : Health Council of the Netherlands, 2002; publication no. 2002/04. p. 11.

<sup>25</sup> Y.A.L. Pijnenburg, E.S.C. Korf, Ph. Scheltens. ‘Diagnostiek van dementie’, in: *Medisch contact*, issue 25, 2002. (via: <http://medischcontact.artsennet.nl/archief-6/tijdschriftartikel/05943/diagnostiek-van-dementie.htm>, consulted on: 28-04-2014).

<sup>26</sup> ‘NHG-Standaard Dementie – Beloop van de ziekte van Alzheimer en vasculaire dementie’ (via: <https://www.nhg.org/standaarden/volledig/nhg-standaard-dementie>, consulted on: 29-04-2014).

<sup>27</sup> ‘Vasculaire dementie’ (via: <http://www.alzheimer-nederland.nl/informatie/wat-is-dementie/vormen-van-dementie/vasculaire-dementie.aspx>, consulted on: 29-04-2014).

scope of dementia because it leaves the substantial impact on the individual and his environment out of the picture<sup>28</sup>; memory impairment, changes in personality and disruption of behavior have weighty effects on both the patient and his relatives. This makes it apparent that the course of dementia differs from disease to disease and from patient to patient. But despite the similar inherent outcome of mental deterioration and thus the loss of competence and the increasingly frequent occurrence of the most common forms of dementia at older age, dementia doesn't necessarily bring about severe suffering in the last phase of life, as was depicted in the fragment from Bernlef's *Hersenschimmen*. The suffering caused by dementia may become more intense during the course of the disease, but it's not uncommon or impossible for suffering to be relieved during the course of the disease. Nevertheless, the suffering that is commonly associated with dementia and the inherent loss of competence instigates some people to compose an advance euthanasia directive as a precautionary measure while they still are competent.

The KNMG published an official standpoint concerning the handling of these advance euthanasia directives. In general they state that euthanasia does not belong to normal medical practice, it's taken to be an exceptional medical procedure and a last resort for those cases in which both the patient and physician acknowledge that the patient's suffering can't be relieved in any other reasonable way. This situation is taken to be exceptionally difficult for the physician because he is confronted with conflicting obligations: "enerzijds de plicht om het leven van de patiënt te eerbiedigen en anderzijds de plicht om (verder) lijden van de patiënt te voorkomen."<sup>29</sup> Because of this the KNMG emphasizes that physicians can never be forced to participate in in this practice, physicians may always refuse cooperation. In a further specification of their standpoint the KNMG expressed the crucial condition that physicians should be able to communicate with their patients: "Als de consulent niet meer met de patiënt zelf kan communiceren, dan kan deze niet vaststellen of aan de zorgvuldigheidseisen is voldaan. Euthanasie of hulp bij zelfdoding is dan niet meer geoorloofd. De medisch professionele norm is op dit punt strikter dan de wet."<sup>30</sup> In practice this implicates that many advance requests for euthanasia of demented patients can't be fulfilled because these patients are no longer able to reaffirm their wish.

Even though the demand for communication isn't required according to the previously displayed legal text, it is strongly defended by the KNMG. This particularly has an effect on the possibility of euthanasia for patients suffering from dementia in a late state. Hans van Delden explicitly argues against euthanizing demented patients by emphasizing obstacles in the majority of the legal due care requirements, which rest on the impossibility for the physician to communicate with patients.<sup>31</sup> This need for communication was also affirmed in research conducted concerning the handling of advance directives by elderly care physicians, which focused on the decision-making process underlying the eventual consent or dissent with the request for euthanasia from a now demented person. The research has shown that physicians have a reluctant attitude towards these directives

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<sup>28</sup> Health Council of the Netherlands. *Dementia*. p. 37.

<sup>29</sup> 'De rol van de arts', in: *Standpunt Federatiebestuur KNMG inzake euthanasie 2003*. p. 7 (via: <http://knmg.artsennet.nl/web/file?uuid=8c5806df-66ba-4c8a-9e68-95052c69a20f&owner=a8a9ce0e-f42b-47a5-960e-be08025b7b04&contentid=41999>).

<sup>30</sup> 'Uitleg', in: *KNMG: een nadere uitleg van het standpunt Euthanasie 2003*. Utrecht, 2012. p. 1 (via: <http://knmg.artsennet.nl/web/file?uuid=18519133-dc94-47d8-97cb-79b03e6b8920&owner=a8a9ce0e-f42b-47a5-960e-be08025b7b04&contentid=111601>).

<sup>31</sup> J.J.M. van Delden. 'The unfeasibility of requests for euthanasia in advance directives', in: *Journal of Medical Ethics*, volume 30, 2004. pp. 447–452. Here: p. 448.

precisely because of the inability to communicate with the patient.<sup>32</sup> Because a severely demented patient is no longer able to competently make an expression about his state of suffering and because there is no consensus among physicians about the extent of suffering of such a patient most physicians do not take dementia to be a ground for euthanasia in itself. However, some think it could be if this patient would be suffering “unbearably and hopelessly from another additional illness.”<sup>33</sup> More fundamentally it is doubted whether an advance directive even is a valid request; “a demented person becomes a psychologically different person and [...] therefore the previously competent person does not have the right to decide about the currently demented person.”<sup>34</sup> I’ll come back to this philosophical concern more thoroughly later on.

It should furthermore be emphasized that euthanasia has a profound effect on physicians, the documentary *Dodelijk dilemma – Euthanasie vanuit doktersperspectief* explicated that euthanasia is not just a medical or technical procedure but that it turns out to be a very intimate act from the perspective of the physician which lies beyond the normal scope of medical care. Physicians who participate in euthanasia have to expand their regular working field of aiming to cure patients<sup>35</sup> and participate in active life-ending. Unmistakably the patient and the physicians form a special bond during this process, in one case a physician even refers to this bond as a kind of friendship that makes him vulnerable. After this physician eventually terminated the patient’s life one can hear he is noticeably affected by this act:

“Het is klaar, het ging technisch heel goed. Ze was rustig, ze was mooi, ze was klaar. En eigenlijk toen in de eerste seconde van het inlopen van spuit één ademde ze niet meer, maar dat was zonder enig geluid, hield ze op met ademen, zonder enig geluid, gewoon... Toen was ze weg. Ja... Enorm opgelucht, ja, en ook verdrietig, want ik heb een vriendin doodgespoten, euthanasie op toegepast. [...] Het went voor geen meter. Dit is het moeilijkste wat je kunt doen.”<sup>36</sup>

The weight of a patients request for euthanasia on his physician is often left underexposed. The termination of life shouldn’t be thought of lightly because it’s not only the most definite choice a patient could ever make but it also has a profound effect on the physician performing the act. Conceivably physicians approach requests for euthanasia cautiously for “[a] request for euthanasia is one of the most intrusive and onerous demands that a patient can make of a physician.”<sup>37</sup> The request has an intrusive character because it leaves the physician in a state of uncertainty, possibly even more in the context of dementia because of the lack of competent communication with the

<sup>32</sup> Marike E. de Boer, Rose-Marie Dröes, Cees Jonker, Jan A. Eefsting, & Cees M. P. M. Hertogh. 'Advance directives for euthanasia in dementia: how are they dealt with in Dutch nursing homes? Experiences of physicians and relatives', in: *Journal of the American Geriatrics Society*, volume 59, issue 6, 2011. pp. 989-996. Here: p. 994.

<sup>33</sup> Mette L. Rurup MSc, Bregje D Onwuteaka-Philipsen PhD, et al. 'Physicians' Experiences with Demented Patients with Advance Euthanasia Directives in the Netherlands', in: *Journal of the American Geriatrics Society*, volume 53, issue 7, 2005. pp. 1138–1144. Here: p. 1143.

<sup>34</sup> Mette L. Rurup. 'Physicians' Experiences with Demented Patients with Advance Euthanasia Directives in the Netherlands', p. 1143.

<sup>35</sup> 'HollandDoc: Dodelijk dilemma – Euthanasie vanuit doktersperspectief', a documentary by Juul Bovenberg, aired on 14-01-2010 at VPRO (via: <http://www.uitzendinggemist.nl/afleveringen/1133983>, consulted on: 23-04-2014), 1:43-1:55min.

<sup>36</sup> 'HollandDoc: Dodelijk dilemma', a documentary by Juul Bovenberg. 50:23-51:34min.

<sup>37</sup> 'Conclusions', in: *The role of the physician in the voluntary termination of life*, June 2011. p. 6 (via: <http://knmg.artsennet.nl/web/file?uuid=9075af1d-e5de-47a1-a139-e07ef4a7c4f4&owner=a8a9ce0e-f42b-47a5-960e-be08025b7b04&contentid=100970>, consulted on: 01-05-2014).

patient, concerning the proper course of action when he is confronted with a request for active life-ending.

### 1.3 The patients' perspective

"Haar eigen euthanasieverklaring ligt bij de huisarts en haar kinderen. 'Ik heb geen standaardverklaring gebruikt, maar zelf een briefje geschreven, omdat ik vind dat je dit soort dingen zelf moet opstellen. Voor mij ligt de grens dat ik niet wil eindigen als een zwaar demente vrouw die haar eigen kinderen niet meer herkent.'"<sup>38</sup>

All our lives will end someday, but while it is obvious that some people would rather not be alive, given the conditions that they are in or foresee in the future, it is unsure *when* and *how* we will die. Many fear the outcome of these undecided factors, perhaps not necessarily because they fear death itself, but particularly because of the element of suffering that could be involved. With the aim of influencing their future some people choose to compose an advance euthanasia directive, they regularly take this directive to compensate the lack of future expression and to secure future medical treatment by involving the active help of a physician in one's death wish. Els Borst was also one of these people who composed an advance directive, as can be read above. She requested euthanasia in case severe dementia would ever cause her to be unable to recognize her children.

An advance euthanasia directive exposes a patient's deep desire concerning the circumstances of his future death and, ahead of time, compensates for his future lack of competence. Even though advance directives are intended for situations in which it is no longer possible for the patient to competently express his wish for euthanasia, many patients are left empty handed when the circumstances of their desired moment of death arise. Patients do not have the right to receive euthanasia and because advance euthanasia directives are rarely complied with they regularly merely seem to provide people with a false sense of security. In order to improve the probability that physicians will comply with a predetermined request for euthanasia people are advised to speak to their physician timely and frequently, as can be read in the patient brochure *Spreek tijdig over uw levenseinde* provided by the KNMG<sup>39</sup>. The KNMG emphasizes that they insist the patient must actively seek contact with his physician and bring his wish to the attention, preferably while he still is in good health<sup>40</sup> and on a regular basis<sup>41</sup> so that possible misunderstandings about his wish are kept to a minimum. In practice this advice particularly applies to a group of vital seniors who are fearful of losing control over their life and future, and "specifically reject the perspective of a disease that causes their identity to unravel and brings with it a loss of competence and independence."<sup>42</sup> These

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<sup>38</sup> Henny de Lange. 'Els Borst - Woede over onrecht is mijn drijfveer', in: *Trouw*, 20-04-1998 (via: <http://www.trouw.nl/tr/nl/5009/Archief/archief/article/detail/2470143/1998/04/20/ELS-BORST---Woede-over-onrecht-is-mijn-drijfveer.dhtml>, consulted on: 05-05-2014).

<sup>39</sup> In collaboration with patient organizations NFK, NPCF, NPV and NVVE and seniors interest groups ANBO, Union BCE and PCOB.

<sup>40</sup> 'Wanneer voert u het gesprek?', in: *Praat tijdig over uw levenseinde*. p. 6 (via: <http://knmg.artsennet.nl/web/file?uuid=d9cba7e6-065b-416e-9b0b-609fec346e0c&owner=a8a9ce0e-f42b-47a5-960e-be08025b7b04&contentid=116526>, consulted on: 03-05-2014).

<sup>41</sup> 'Praat over uw euthanasieverzoek', in: *Praat tijdig over uw levenseinde*. p. 20.

<sup>42</sup> Cees M. P. M. Hertogh, Marika E. de Boer, Rose-Marie Dröes & Jan A. Eefsting. 'Would We Rather Lose Our Life Than Lose Our Self? – Lessons From the Dutch Debate on Euthanasia for Patients With Dementia', in: *The American Journal of Bioethics*, 2007 Volume 7, issue 4, pp. 48-56. Here: p. 50.

vital seniors who compose advance euthanasia directives as a precautionary measure are represented in the current debate, for instance by the NVVE.

However, the voices of patients who are currently suffering from dementia seem to be absent in the debate. This is a shortcoming for their experience of and their perspective on dementia could challenge prevailing prejudices surrounding dementia and the anticipated component of suffering. Research that focused on literature in which people with dementia were given a voice as they were enabled to express their own experiences, led to the conclusion that there was no solid support concerning “the widespread assumption that dementia is necessarily a state of dreadful suffering, or a disaster without consolation”<sup>43</sup>. Of course, as was also confirmed by this study, dementia is regularly accompanied by negative emotions; patients often realize that something is wrong and that abilities are lost, which can, for instance, evoke fear, insecurity and confusion. But as dementia is known to slowly progress over time instead of appearing suddenly, most people try to continue their regular way of living while gradually adjusting to the changing situation.<sup>44</sup> The actual experience of dementia turns out to be not as dramatic as the biased prospect which many people who compose an advance euthanasia directive hold. People are able to handle their disease in a way that was not foreseen, so there is a chance that “people with dementia will not act in accordance with their earlier values and anticipatory beliefs regarding a life with dementia”<sup>45</sup> and this alteration could impede the value of their directive. Even though this study considers a large quantity of experiences and reveals that dementia on average doesn’t necessarily bring about severe suffering it does neglect the individuality of suffering; from the patients’ perspective suffering is singular. The patient’s awareness concerning the prospect of insurmountable future mental decline, regardless of its accuracy, can bring about actual suffering in itself, in the same way as “the courts have already accepted that the prospect of impending humiliation could qualify as unbearable and hopeless suffering”<sup>46</sup> in the context of diseases such as AIDS and Huntington’s disease. Furthermore, patients can also suffer from undergoing the gradual loss of one’s self over the course of the disease. Patients are to some extent aware of this loss, and it is only in the last stages of the disease that one completely loses awareness. This implies they will also lack awareness of their illness at that final point, but this however does not provide consolation for those who compose an advance euthanasia directive, as this phase in which their self has derogated is the actual phase they tried to avoid. Their identity and everything they ever stood for is dismantled step by step by their disease. Dementia slowly manifests itself in patients, and precisely because of that Govert den Hartogh argues that these patients suffer tremendously: “juist omdat hij niet meteen volledig ophoudt het subject te zijn van zijn eigen ervaringen, vaak ervaringen heeft van zeer ernstig lijden.”<sup>47</sup>

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<sup>43</sup> Marike E. de Boer, Cees M. P. M. Hertogh, Rose-Marie Dröes, Ingrid I. Riphagen, Cees Jonker & Jan A. Eefsting. 'Suffering from dementia – the patient’s perspective: a review of the literature', in: *International Psychogeriatrics*, 2007, volume 19, issue 6, pp. 1021–1039. Here: p. 1033.

<sup>44</sup> Marike E. de Boer, Cees M. P. M. Hertogh, et al. 'Suffering from dementia – the patient’s perspective'. p. 1034.

<sup>45</sup> Marike E. de Boer, Cees M. P. M. Hertogh, et al. 'Suffering from dementia – the patient’s perspective'. p. 1034.

<sup>46</sup> Cees M. P. M. Hertogh, Marike E. de Boer, e.a. 'Would We Rather Lose Our Life Than Lose Our Self? p. 51.

<sup>47</sup> Govert den Hartogh. 'Dementie kan ondraaglijk zijn', in: *Medisch contact*, issue 12, 2012, pp. 704-706 (via: <http://medischcontact.artsennet.nl/archief-6/tijdschriftartikel/112386/dementie-kan-ondraaglijk-zijn.htm>).

## 2. Personal identity and the someone else problem

“Haar ‘ik’ valt weg. Dat ‘iets’ dat een persoon zo herkenbaar zichzelf maakt. Het hele repertoire van gewoontes, manieren van spreken, slapen, lopen, staan, het verandert allemaal. Een soort van mengelwezen ontstaat uit trekken, gedragingen die ik me als de hare kan herinneren, en andere, die onbekend en bevreemdend zijn, alsof een parasitair bewustzijn zich in haar vlees ontpopt.”<sup>48</sup>

Dementia evokes changes of personality in patients; this becomes apparent in the alteration of behavior, cognition and emotions. The stable pattern of features that are typical and characteristic for a specific person gets ruptured due to their illness. Patients will, at least generally in the initial phase of dementia, notice that things about them are changing, and outsiders, such as relatives and physicians, will also be confronted with the effects of the psychological changes that gradually occur. This for instance becomes apparent in the personal description Erwin Mortier gave of his mother’s deterioration due to her suffering from Alzheimer’s disease, as was cited above. The unique person she was to him evidently started to change, her characteristic habits transformed into unfamiliar behavior; her ‘I’ is omitted. The transformation that Mortier describes in his literary approach hints at a fundamental problem, for is this unfamiliar woman still his mother?

The documentary *Als ik dement ben, wil ik dood*<sup>49</sup> portrayed another woman, Mrs. Joukje van der Enden who suffered from dementia and permanently lived in a nursing home, unable to speak and barely able to recognize her relatives. Even though she had composed an advance euthanasia directive precisely as prevention for if she would ever come to be in these circumstances, she was judged to be no longer eligible for euthanasia. In a clarification of this verdict managing director Lode Wiggersma of the KNMG not only explicated that they hold that euthanasia can only be carried out in the early stages of dementia, because at that point a physician can still be reassured by the patient that he still endorses his wish for life-ending.<sup>50</sup> But even more fundamentally he stated that the perceived change in the patient’s personality impedes a physician to gain affirmation that the current patient would endorse the same directive as the person who drafted the advance directive in the first place; they hold the view that the current patient should be granted protection.<sup>51</sup> Along this line of reasoning Hans van Delden indicates that this troublesome continuity of a person indicates that advance directives are inherently ethically problematic.<sup>52</sup>

While many patients presuppose that their advance directive secures their future treatment, the inevitable transformation they undergo due to their suffering from dementia is generally taken to impede physicians to comply with the predetermined request. As a byproduct of this problematic situation people may find themselves strained to end their lives earlier than they initially requested, in the earlier stages of their disease. Only very rarely are patients suffering from dementia in a late state judged to be able to competently express, in the form of gestures, sounds or words, a desire for life-ending and are euthanized based upon this. However, it comes as no surprise that these rare and exceptional instances provoke strong emotional reactions, such as Bert Keizer’s response after a

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<sup>48</sup> Erwin Mortier. *Gestameld liedboek – moedergetijden*. Amsterdam : De Bezige Bij, 2011. p. 19.

<sup>49</sup> ‘Als ik dement ben, wil ik dood’, a documentary by Zembla, aired on 14-02-2013 at Vara (via: <http://zembla.incontxt.nl/seizoenen/2013/afleveringen/14-02-2013>, consulted on: 05-05-2014).

<sup>50</sup> ‘Als ik dement ben, wil ik dood’, Zembla. 05:48-06:54min.

<sup>51</sup> ‘Als ik dement ben, wil ik dood’, Zembla. 11:23-12:00min.

<sup>52</sup> Hans van Delden. ‘The unfeasibility of requests for euthanasia in advance directives’. p. 450.



woman suffering from dementia in a late state has been euthanized<sup>53</sup>. Without going into too much detail about this particular case Keizer in general refers to the euthanizing of these patients as if they were pets, being put down by their owners. From his perspective it's not the patient who experiences suffering, but his relatives and it's them who initiate life-ending because they don't want to experience the burden. He deems it to be despicable that physicians would be forced to execute the dirty work when it is already too late, precisely because of the difficulties that arise concerning the psychological change that affected the patient.

However, antedating the execution and putting time pressure on patients leaves the fundamental problem of persistence of personal identity essentially disregarded and unresolved. It is feared that patients might change into someone else once they are subjected to dementia, this could lead to instances in which an advance directive from one person essentially determines the treatment, the one-off ending of a life, of another person. The previously competent persons seems to be replaced, as has been described before in the cases of both Mortier's mother and Mrs. van der Enden, by a completely different person, or, in other words: personal identity is not taken to persist over time. I take this problem of personal identity to play a crucial role in determining the status of advance directives, for if this change truly occurs it could derogate the value of the advance euthanasia directive as it is deemed to be unacceptable that the request of one person would lead to the death of someone else. This problematic situation instigates 'the someone else problem', which refers to cases in which patients who undergo substantial psychological change end up to be separate individuals diverged from the initial persons. This has led me to the following question:

Does 'the someone else problem' form a valid argument against euthanasia in the context of dementia?

In order to answer this question I'll analyze the someone else problem in the light of different theories on personal identity, and I'll critically evaluate each of these theories. The first theory I'll discuss is the psychological approach of personal identity, which indeed exposes a fracture in personal identity over time. Hereafter I'll focus on the biological approach of personal identity, and argue that this latter theory is able to refute the someone else problem in the sense that it guarantees continued existence over time. Lastly, I'll focus on narrative identity, which is not so much concerned with existence as such but with the quality of existence, and argue that this gives rise to the someone else problem as people's values could change due to the occurrence of dementia, even their valuation of euthanasia.

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<sup>53</sup> Bert Keizer. 'Dit was geen euthanasie, want er was geen verzoek', in: *Trouw*, 11-02-2012 (via: <http://www.trouw.nl/tr/nl/4328/Opinie/article/detail/3187580/2012/02/11/Dit-was-geen-euthanasie-want-er-was-geen-verzoek.dhtml>).

## 2.1 The psychological approach

“[a Person] is a thinking intelligent Being, that has reason and reflection, and can consider it self as it self, the same thinking thing in different times and places; which it does only by that consciousness, which is inseparable from thinking, and as it seems to me essential to it: [...] For since consciousness always accompanies thinking, and ‘tis that, that makes every one to be, what he calls *self*; and thereby distinguishes himself from all other things; in this alone consists *personal Identity*”.<sup>54</sup>

John Locke’s 17<sup>th</sup>-century conception of personal identity still has its influence on modern day philosophy. In this conception the persistence of identity is based on one’s personhood, identity consists in psychological continuity. Locke characteristically conceived a person to possess intelligence, reason, reflection and thus consciousness, which is inherently linked to this for Locke holds the belief that it would be impossible for someone to perceive something without this being accompanied by an indispensable awareness of it, without perceiving that he does. Consciousness is hence deemed to be the fundament of personal identity; a person’s identity depends on the extension of consciousness back in time to past thoughts or actions performed by the same rational being. Personhood rests solely on psychological traits, and the continuity of this is of crucial importance to one’s personal identity. The same self exists throughout time; from Locke’s perspective the self who now reflects on memories of the past is the same self as the one who lived through the actual actions.

A current person is identical to a past person if one’s consciousness can be extended backwards to this past, personal identity exists because of this psychological relation. I am identical to a past version of me because I can remember his actions and my identity exists in this continuity; X at  $t_1$  is the same person as Y at  $t_2$  because X is psychologically continuous with Y. Psychological continuity guarantees numerical continuity over time, one remains to be one and the same person as long as he has a psychological connection to a past version of him.

Various objections have been made to this conception of personal identity. To start with, Joseph Butler argued that consciousness could never constitute personal identity: “one should really think it self-evident, that consciousness of personal identity presupposes, and therefore cannot constitute personal identity, any more that knowledge, in any other case, can constitute truth, which it presupposes.”<sup>55</sup> Butler’s reflection on personal identity is a quest for consisting equality over time. Although one’s memories of past events do reveal and ascertain the past, Butler states that it additionally also already displays one’s identity in these moments, an identity that is one and the same. Analogous he gives examples of two triangles being compared and the sum of two times two being compared with the number four; in both examples it is immediately clear that the objects share the same identity, both triangles and both sums are of equal essence. This equality is already posited in personal identity, consciousness presupposes this personal identity for one can only remember a past experience because it is his memory, a memory of an experience doesn’t make it belong to someone. This is in clear contrast with Locke’s conception of personal identity. While Locke discerned two different persons who, by memory, share the same past and thus at that point their identity is perceived, Butler convincingly conceives that the consciousness of a past experience

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<sup>54</sup> John Locke. *An Essay concerning Human Understanding* [edited by Peter H. Nidditch]. Oxford : Clarendon Press, 1975. p. 335.

<sup>55</sup> Joseph Butler. ‘On personal identity’, in: *Analogy of Religion*. New York : Harper & Brothers publishers, 1860. p. 324.



doesn't make the past experiencer the present person, the person must be an unaltered substance that can remember his past experiences as they already are his own.

Another objection is closely related to this first remark, this has to do with the inevitable discontinuity of memories. One could suffer from forgetfulness, memories of certain events might fade over time and in general one is unable to recall detailed memories of every past experience, Locke does endorse that this takes place, as he writes: "there being no moment of our Lives wherein we have the whole train of all our past Actions before our Eyes in one view [...] we [are] losing the sight of our past selves"<sup>56</sup> Edward Olsen refers to a woman who received a fine for overdue library books while she was a young student to explicate the problematic aspect of discontinuity for Locke's personal identity theory.<sup>57</sup> When she is a middle-aged lawyer this woman still remembers paying the fine back in the days when she was a law student, as time goes by she becomes an elderly lady who does remember her former law career but has however no memory of ever paying this fine, she has forgotten this past event. When strictly following the memory criterion this would lead to the absurd conclusion that the middle-aged lawyer is the same person as the young student, and that the elderly lady is the same person as the middle-aged lawyer, but that the elderly lady oddly enough is not the same person as the young student. What could provide a solution to this impediment in this approach of personal identity is the idea that "one may certainly have direct memories of some past stage that itself had direct memories of an earlier stage, and so on, until every stage in the life is linked by a chain of overlapping direct memories."<sup>58</sup> This approach effectuates a continuous chain of memories by referring to quasi-memories<sup>59</sup> as Derek Parfit calls them, continuity exists because a past version of oneself had direct memories of a certain event; in this case the elderly lady remembers herself as a middle-aged lawyer who in her turn had a memory of paying the fine as a young law student, and thus the elderly lady would still be the same person as the young student.

Up and until now I have referred to memories as if they were genuine and stable personal experiences of certain past events, it is however questionable whether this is a rightful interpretation of memories. Various studies have been conducted concerning the reliability of memories. Studies of flashbulb memories are predominant; these are vivid long-lasting memories of unexpected consequential events. The Twin Tower attack in the USA is an exemplary event that has been discussed in many studies. Talarico and Rubin<sup>60</sup> contacted a group of students on the day after the 9/11 and tested their memory of hearing about the attacks the day before. Later on researchers interviewed their participants a second time asking identical questions after an interval of one week, six weeks or 32 weeks to determine the course of forgetting. During the evaluation a decline in consistent memory details was found despite the vividness and confidence with which the

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<sup>56</sup> John Locke. *An Essay concerning Human Understanding*. p. 336.

<sup>57</sup> Eric Olson. 'Personal Identity', in: *The Stanford Encyclopedia of Philosophy* (Winter 2010 Edition), Edward N. Zalta (ed.), via: <http://plato.stanford.edu/archives/win2010/entries/identity-personal/>, consulted on: 14-05-'14.

<sup>58</sup> David Shoemaker. 'Personal Identity and Ethics', in: *The Stanford Encyclopedia of Philosophy* (Spring 2014 Edition), Edward N. Zalta (ed.), via: <http://plato.stanford.edu/archives/spr2014/entries/identity-ethics/>, consulted on: 14-05-'14.

<sup>59</sup> Derek Parfit. '80. Does psychological continuity presuppose personal identity?', in: *Reasons and Persons*. Oxford : Oxford university press, 1987.

<sup>60</sup> J. M. Talarico. & D.C. Rubin. 'Confidence, not Consistency, Characterizes Flashbulb Memories,' in: *Psychological Science*, volume 14, issue 5, 2003. pp. 455-461.

participants described their memories overtime. Hirst et al.<sup>61</sup> similarly interviewed 3.000 adults with similar questions about 9/11. Participants were interviewed at an interval of one week, 11 months and 35 months after the attack. They found that inconsistent flashbulb memories reported in one survey were sometimes repeated on the next survey, while others corrected their inaccurate memories of the event. These studies make clear that it is not unusual for people to alter or even make up memories; they are for instance unable to accurately recollect what happened and significantly reshape their memories or forget about certain events completely. This distortion of memories implies that what a person remembers at a certain moment in time might differ from a previous memory about the same event to such an extent that it might not be able to retrace this to the same person. One does not unequivocally inherit the memories of his predecessor and this could both cause fractures between past and current versions of a person when one forgets and loses a memory but also might create bonds between past and current versions of a person due to incorrect memories. This destabilizes the reliability of memories as a foundation for personal identity in general as the alteration or disappearing of memories weakens the required equality of identity. Even quasi-memories can't overcome these difficulties because a direct memory of a past experience that has never taken place doesn't make me that past person despite the direct memory connection that can be established. In an extreme interpretation this would imply that any person never is the same person as he was in the past and will never be the same person in the future for memories are not unambiguously transferred to one's future self, let alone in the context of dementia.

So far I have interpreted Locke's writings on personal identity, in which he thoroughly focuses on consciousness, as a theory on memory connections throughout time. Marya Schechtman however provides a different interpretation of Locke's theory, her interpretation leans on an affective account of consciousness in which she focuses on the continuity of consciousness in relation to pleasurable and painful experiences as she derives from Locke that consciousness is the faculty whereby one experiences these affections.<sup>62</sup> Current actions are part of one's consciousness because they cause pleasure or pain at this very moment, but the same goes for past actions; consciousness persists through time because it reaches back in time as one can still feel effects of past actions. This view surprisingly does not demand explicit accuracy or even existence of memories of past experiences, "individuals can repress explicit memory of particular experiences and yet feel associated emotions. [...] Sometimes it is not specific events but rather global characteristics of the past that condition the present."<sup>63</sup> This observation thus indicates that one's past does not consist of a sequence of memories of certain events, if these memories even persist over time at all. Above all Schechtman argues that past events can still be the past of one's current consciousness for they can still affect one by evoking emotions in the present. This is a steppingstone to Schechtman's approach of her narrative identity theory in the sense that she takes this inheritance from the past to provide one with a script, "an idea of who we are and what kind of story we are living"<sup>64</sup>. I'll come back to this approach later on. All in all, it is not unthinkable that these emotional affections will also be ruptured due to one's suffering from dementia as the entire detachment of the past is greatly accelerated and aggravated in these circumstances.

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<sup>61</sup> William Hirst et al. 'Long-Term Memory for the Terrorist Attack of September 11: Flashbulb Memories, Event Memories, and the Factors That Influence Their Retention,' in: *Journal of Experimental Psychology: General*, volume 138, issue. 2, 2009, pp. 161–176.

<sup>62</sup> Marya Schechtman. *The constitution of selves*. Ithaca : Cornell University Press, 1996. p. 108.

<sup>63</sup> Marya Schechtman. *The constitution of selves*. p. 110.

<sup>64</sup> Marya Schechtman. *The constitution of selves*. p. 111.

Even though it has become evident that Locke's approach of personal identity is not unproblematic, this theory gives rise to the prevailing interpretation of the someone else problem in which numerical continuity is threatened: "in certain cases in which a patient undergoes massive psychological change, the individual who exists after such change is literally a numerically distinct individual from the person who completed the directive."<sup>65</sup> If one would strictly follow the psychological approach as a ground for persisting personal identity over time this would imply that people who suffer from dementia change into different persons as their consciousness can no longer reach back in time, for it becomes apparent that mental features get disrupted in this phase of life. The demented patient undergoes tremendous change and turns into another person, or in other words, one loses the form of consciousness that is reserved to persons in Lockean tradition as dementia causes one to part from the past person one was and evoke loss of personhood. However, as will become apparent in the following paragraph on the biological approach of personal identity I will argue that numerical continuity of identity is not in essence threatened by this theory on psychological continuity as I take this to lean on an inadequate conception of the essence of people.

## 2.2 The biological approach

"we human persons – and, for that matter, human beings who are not persons – are essentially human *animals*, members of the species *Homo sapiens*. Human animals do not *constitute* us [...] we *are* human animals."<sup>66</sup>

In contrast with the previous conception the persistence of identity is in this regard based on one's biological essence, one is essentially viewed to be a human animal. In this context Degrazia regularly refers to *human* identity instead of *personal* identity as the latter might misleadingly refer to the conception of humans essentially being persons or to one's human identity in the phase of being a person.<sup>67</sup> Personhood is taken to be merely a phase in existence as in some instances in life humans don't exist as a person and therefore this can't be one's essence, we only temporarily are persons. There was a phase in the past in which humans were not yet persons, this could for instance be the time in which one was still a child who had not yet developed a complex form of consciousness, or, even further back in time, the phase in which one still was a fetus; this also indicates that there might come a moment in which one reversely is no longer a person, for instance severely demented humans. In contrast with person essentialism I don't take these alterations to change humans into different beings, they just mark different stages in life.<sup>68</sup> This biological approach does not constrain the moral status of humans who don't possess personhood, for all humans fall under the same denominator of a human animal. Furthermore, DeGrazia does not claim that humans essentially belong to the specific species of *Homo sapiens* as he does not rule out the possibility of humans already being, or being transformed into, a member of another biological kind; he doesn't strictly demarcate the boundaries of a specific species but emphasizes that all humans are essentially

<sup>65</sup> David DeGrazia. 'Advance directives, dementia, and 'the someone else problem'', in: *Bioethics*, volume 13, issue 5, 1999. pp. 373-391. Here: p. 374.

<sup>66</sup> David DeGrazia. *Human identity and bioethics*. Cambridge : Cambridge university press, 2005. p. 48.

<sup>67</sup> David DeGrazia. *Human identity and bioethics*. p. 8.

<sup>68</sup> This also implicates that there might be humans, for instance (severely) mentally disabled, who will never develop into the stage of personhood as they don't have the capacity for consciousness.

animals of some kind.<sup>69</sup> The continuity of our identity does not lie in us fundamentally being persons, but lies in us essentially being human animals throughout our existence. We can't exist in a non-animal form and from the biological perspective a past animal and a current animal are therefore taken to be identical if they share a single animal life. So even if one's values, desires and wishes evaporate in losing his personhood, one still numerically continues to be the same being, the same animal that one has always been.

The greatest threat to this conception is the so-called 'transplant intuition', in this case the cerebrum of one human, a large part of the brain that is essential for human consciousness<sup>70</sup>, is transplanted into another body. This other body hereby takes over the psychological traits of the first person while the body of the cerebrum-less being is also kept alive. The troubling question is: what happened to the person in question? This might seem like a futuristic and highly hypothetical case, it is questionable if it would be practically possible to select and remove this, and only this, specific part of the human brain. But when considering the recent rapid developments in both medical and technical capabilities, the possibility of brain transplantation in the near future might not be too farfetched.<sup>71</sup> Intuitively most people would hold that the body which now houses the cerebrum would be the actual person, as this is the being that recognizably inherited the characteristic psychological<sup>72</sup> traits which are thus taken to be essential for one's continued existence. This is an appealing perception because this second being would be able to recollect past experiences. If one would however follow the biological approach one would have to maintain that the actual person is still to be found in the cerebrum-less body. This example seems to have further implications concerning one's moral responsibility:

"Suppose further that I had committed some crime and then donated my cerebrum in this way. The person who woke up would seem to remember my crime and anticipate enjoying getting away with it for a while, but if identity is what's necessary for responsibility, he could not be responsible for my actions, on the Biological Criterion, and so he wouldn't deserve blame or punishment for the crime."<sup>73</sup>

The difficulty in this situation is that the person who is carrying the cerebrum of a criminal and who is, through memory, conscious of the past criminal offence and thus has a psychological relation to it is not deemed to hold any responsibility for these past actions from the biological conception on identity. I take this to morally unjustly safeguard someone from, in this case, prosecution while this person can evidently be linked to a crime, for who else would have exact memories of the execution of a crime but the perpetrator. Because one won't be held responsible for previous actions due to a lack of biological continuity, despite there being an evident link between the past event and the perpetrator, I take the biological criterion to be unsatisfactory in this example. DeGrazia by-passes

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<sup>69</sup> David DeGrazia. *Human identity and bioethics*. pp. 48-49.

<sup>70</sup> I am well aware that many animals, especially vertebrates, have a functioning cerebrum as well even though their brain development and characteristics differ from the human brain. This is enough reason for DeGrazia to ascribe sentience and desires to some animals (see: David DeGrazia. *Taking Animals Seriously: Mental Life and Moral Status*. Cambridge : Cambridge University Press, 1996. pp. 135-136.). As I take this consideration to lie outside the scope of my thesis project, I'll not go into further detail about this at this point.

<sup>71</sup> Various trans-humanists already anticipate on this possibility by storing their brain after death in the hope of one day being transplanted back to life. See for instance: David Gelles. 'Immortality 2.0', in: *Futurist*, volume 43, issue 1, 2009. pp. 34-41.

<sup>72</sup> This differs somewhat from Locke's conception of personhood as he does not take this to be essentially related to one's brain.

<sup>73</sup> David Shoemaker. 'Personal Identity and Ethics'.

this criticism by stating that “in the world as we know it, psychological continuity requires continuation of the agent’s (biological) life. Nor does it matter much that one may continue to live without any longer being morally responsible – say, if one is severely demented or comatose.”<sup>74</sup> In instances of being demented or comatose one’s consciousness of the past is interrupted, in this context people are therefore generally eventually held to be no longer responsible for past actions.<sup>75</sup> In this latter case it is evident that the psychological continuity of a person is strictly bound to his biological continuity and it becomes evident that biological continuity does not guarantee psychological continuity. This however evades the problem of the previous example; even though such brain-transplantations aren’t being carried out yet, the inability to remove this remaining “theoretical thorn”<sup>76</sup> is a shortcoming in the biological approach to personal identity. I don’t take this to be anything more than a theoretical thorn that doesn’t affect the world as we know it. Currently it suffices to say that biological continuity is a necessary condition for psychological continuity.

Apart from this theoretical remark, personal identity is proven to be persistent over time when viewed from this biological conception. The psychological change that a person may undergo doesn’t affect his continuity of existence as a human animal throughout time, for one is only temporarily a person but can never lose his essence of an animal in his lifetime; this refutes the someone else problem. Personal identity is biologically persistent over time for one continues to be numerically identical over time; X at t1 is the same person as Y at t2 because X is biologically continuous with Y. This approach is however merely concerned with existence as such and not with the quality of one’s existence, in this regard it only provides a limited perspective on human existence. I’ll discuss this in greater detail when explicating the narrative approach on personal identity.

## 2.3 The narrative approach

“Nearly everyone wants more than maintaining numerical identity, or merely surviving. [...] we human persons want, at a minimum, to retain the capacity for consciousness – to continue to be able to have experiences. But we also want to avoid a terribly low quality of life, or quality of experiences, so we prefer death to survival with extremely poor experiential welfare and no prospects for improvement.”<sup>77</sup>

People biologically persist over time as numerically distinct individuals; even though this secures existence it doesn’t guarantee any certain quality of life. Nevertheless people are not so much concerned with *if* they exist, but more precisely with *how* they exist, now and in the future. They are concerned with the quality of their existence. In contrast with the previous approaches of identity the narrative approach distances from numerical continuity of a person and instead focuses on

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<sup>74</sup> David DeGrazia. *Human identity and bioethics*. p. 60.

<sup>75</sup> In this regards, though I’m well aware that this is not entirely uncontroversial, one could for example think of Nazi-criminals from The Second World War who are no longer convicted for past actions because they are severely demented and thus no longer held to be responsible for past actions. A recent case: “De Duitse overheid keert een schadeloosstelling van 5.350 euro uit aan Hans Lipschis, oud-bewaker van concentratiekamp Auschwitz. Lipschis zat zeven maanden in voorarrest, maar de rechtbank in Ellwangen oordeelde eind februari dat hij dement is en niet kan worden berecht.” (---. ‘Oud-bewaker Auschwitz krijgt schadevergoeding’, in: *De Volkskrant*, 10-04-2014. p. 6.)

<sup>76</sup> David DeGrazia. *Human identity and bioethics*. p. 54.

<sup>77</sup> David DeGrazia. *Human identity and bioethics*. p. 79.

personal qualities such as characteristics, values, experiences and actions in a self-told narrative life story. The general claim that can be ascribed to this approach of personal identity is the conception that what makes any of these personal traits properly attribute to someone and hence form a part of one's identity is its accurate inclusion into one's life story.

The fundamental question that underlies this conception is 'who?'<sup>78</sup> 'who am I?'<sup>79</sup>; in this respect DeGrazia declares that this question is fundamentally related to self-creation, it induces people to reflect on their lives, on how they should lead it and on what is most important in life; this can thus be seen as an understanding of identity that concerns people in everyday life.<sup>80</sup> Similarly Charles Taylor emphasizes that this question evokes the need for orientation about what is good and bad in life and about what truly has meaning and importance and what does not. This question brings about self-understanding of one's moral orientation that is indispensable of personal identity.<sup>81</sup> Identity has the function of providing a framework or horizon of orientation as it allows one to discern between what is and what is not truly meaningful in answering the fundamental question of who we really are, and thus seems to leave room for authenticity as one ought to be true to his identity. The modern notion and importance of authenticity in relation to identity, as Taylor describes it, stems from a higher moral ideal, the ideal of authenticity. This ideal entails that self-fulfillment, in the modern sense of the word, and being true to oneself are not merely desires that one trivially happens to have, but desires that one ought to have. The origins of this moral force behind the culture of authenticity can be traced back to the eighteenth-century romantic idea that people possess an inherent moral compass that instinctively dictates what is right and what is wrong. Being in touch with oneself thus originally serves the purpose of being able to discern between good and bad. Currently the moral accent of the inner voice is strongly emphasized and has taken on "independent and crucial moral significance. It comes to be something we have to attain to be true and full human beings."<sup>82</sup> This conception of narrative identity concerns a specific interpretation of selves in a necessarily ethical context; people are living biological organisms but they are only taken to be selves "insofar as we move in a certain space of questions, as we seek and find an orientation to the good."<sup>83</sup> This self continues to be developed over time in relation to his surroundings, in relation to others and the social environment, and this implies that selves not only fundamentally reflect on who they are but also on what one wants to become in moving towards the good. As we live in an ever changing world that challenges people with new events and as people's experiences become more mature over time, life, and thereby identity, can't be framed in one moment by answering the question of who we are, but should incorporate the change of what we were and are to become and should be viewed as a meaningful and harmonious unfolding narrative story. Narrative identity rests on the coherence and wholeness of different values and experiences throughout life which are unified in a self-composed narrative and essentially gives meaning to these past events by incorporating and relating them to other events and the overarching life-story.

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<sup>78</sup> Charles Taylor. *Sources of the self – the making of modern identity*. Cambridge : Cambridge university press, 1989. pp. 27-29.

<sup>79</sup> David DeGrazia. *Human identity and bioethics*. p. 78.

<sup>80</sup> David DeGrazia. *Human identity and bioethics*. p. 113.

<sup>81</sup> Charles Taylor. *Sources of the self*. p. 29.

<sup>82</sup> Charles Taylor. *The ethics of authenticity*. Cambridge, Massachusetts : Harvard university press, 2003. p. 26.

<sup>83</sup> Charles Taylor. *Sources of the self*. p. 34.

Until now the conception of narrative identity, largely discussed from the perspective of Taylor, should be seen as a “quest”<sup>84</sup> in which everyone necessarily orients themselves towards the good and thereby determines the path of life they ought to take. Marya Schechtman however advocates that this conception of narrative identity is too demanding as she states that people regularly don’t have a clear conception of their life path ahead or the direction they want to take it in, and it is very well possible for life to be meaningful or good without having such an overarching conception.<sup>85</sup> In a more moderate way Schechtman endorses a ‘narrative self-constitution view’ which she takes to consist of the two basic claims. The first claim is that “we constitute ourselves as persons by forming a narrative self-conception according to which we experience and organize our lives.”<sup>86</sup> The experiences we have thus don’t stand on their own, but generally automatically find their place in a larger ongoing narrative story of one’s life. Schechtman takes this narrative to be bound to a ‘reality constraint’ in the sense that a narrative can’t outgo the physical limitations to which humans are bound and an ‘articulation constraint’ that concerns the ability to meet an explanatory obligation as to how and why one has taken his life into a certain direction. Schechtman nevertheless seemingly tries to avoid this latter constraint to correspond to the ‘quest’ or life-goal that she criticized in the work of Taylor. As I mentioned earlier, Schechtman considered Taylor’s conception of narrative identity to be too demanding as not everyone has a clear conception of the direction they want to take their life in while they can still have a meaningful or good life without this. The articulation constraint nevertheless forces people to develop some sense of orientation in life in order to be able to clarify one’s life path and articulate one’s own narrative. On the one hand Schechtman pleads that the development of one’s self narrative shouldn’t merely be a background process, but on the other hand it must neither take the form of an active project<sup>87</sup> like the quest that Taylor described. Schechtman’s theory thus intermediates between the two extremes by posing some explanatory obligations as “one should not simply be at a loss”<sup>88</sup>. The second central claim of Schechtman’s view is that in order for experiences to be included in one’s narrative one needs to have empathic access to them; with this she refers to the need for one to have an “affective connection to the past, together with its behavioral implications”<sup>89</sup> in the present. While radical psychological change is generally taken to bring about the loss of one’s identity, the concept of empathic access avoids this pitfall to some extent as one’s psychological characteristics largely, though not necessarily completely, persist over time. She gives an example of an instance in which a mother “sees her daughter making some of the same choices she once did she may not approve, but she will have a keen sense of what drives her, and of how disapproval from her elders will sound”<sup>90</sup>. Even though the mother remembers and recognizes the past excitement of the choices she once made, she has also grown older and wiser and has adjusted some of her earlier beliefs and values. The mother has empathic access to her past; her past psychological characteristics are still present while she has altered over time. Schechtman interprets this continuity as persistence of identity over time despite

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<sup>84</sup> Charles Taylor. *Sources of the self*. p. 52.

<sup>85</sup> Marya Schechtman. ‘Stories, lives, and basic survival : a refinement and defense of the narrative view’, in: *Royal Institute of Philosophy Supplement*, volume 60, 2007. pp. 155-178. Here: p. 161.

<sup>86</sup> Marya Schechtman. ‘Stories, lives, and basic survival’. p. 162.

<sup>87</sup> Marya Schechtman. ‘Stories, lives, and basic survival’. p. 163.

<sup>88</sup> Marya Schechtman. ‘Stories, lives, and basic survival’. p. 163.

<sup>89</sup> Marya Schechtman. ‘Emphatic access : The missing ingredient in personal identity’, in: *Philosophical Explorations: An International Journal for the Philosophy of Mind and Action*, volume 4, issue 2, 2001. pp. 95-111. Here: p. 102.

<sup>90</sup> Marya Schechtman. ‘Emphatic access’. p. 102.

undergoing some change and takes this persistence to continue as long as one is able to maintain sympathy for recalled past objectives that can still be shared. The change that one undergoes can coherently be conjoined in an overarching narrative because of this continuing empathic access to the past. The inherent vagueness of the concept of 'sympathy' however does leave room for discussion about whether empathic access is truly continuous.

Over time everyone constructs his own personal narrative life-story that includes past experiences, personal beliefs and values, and also desires for the future. Schechtman emphasizes that people generally anticipate on the future with a healthy anxiety<sup>91</sup> that drives people to actively orientate on the way the future will realistically be throughout their narrative. Present persons have a clear interest in having a concern about the future and anticipating on it because "what makes a future one's own on this view is that its anticipated character can cause pleasure or pain in the present."<sup>92</sup> This concern shouldn't be reduced to a single moment in which one worries about the future and alters the present by either causing pleasure or pain. Instead one's narrative self transcends the temporary self and "brings into being a temporally extended subject who has this concern for her whole self."<sup>93</sup> It is one's narrative life-story as a whole that counts, this story binds all personal values and beliefs, and it is the story as a whole that gives meaning to certain events, including one's life ending. This narrative identity presupposes numerical identity, "we cannot continue to exist as persons unless we continue to exist."<sup>94</sup> This indicates that one's narrative identity can't persist over time if he would not continue to persist as the same being over time. But physical continuity neither guarantees narrative continuity; when one numerically survives his loss of personhood due his suffering from dementia he might no longer be able to qualitatively control his storyline. This latter development indicates that one could change into someone else once he is gradually torn away from his personal narrative despite his physical persistence. On a qualitative level the someone else problem comes into play again, I'll come back to this later on.

## 2.4 The someone else problem

In this chapter I have discussed different theories of personal identity in order to provide an answer to the question:

Does 'the someone else problem' form a valid argument against euthanasia in the context of dementia?

The concern that patients might change into someone else once they are subjected to dementia is predominant in current discussions surrounding euthanasia in the context of dementia. Especially the fear that patients gradually diverge from their competent personhood and ultimately turn into an incompetent someone else as they undergo substantial psychological change is ubiquitous, as has been described before. This psychological change seems to lead to the presupposition that the person who originally requested euthanasia but has come to suffer from dementia is eventually replaced by a separate individual. This is what I referred to as the someone else problem. If the

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<sup>91</sup> Marya Schechtman. *The constitution of selves*. p. 156.

<sup>92</sup> Marya Schechtman. *The constitution of selves*. p. 155.

<sup>93</sup> Marya Schechtman. *The constitution of selves*. p. 156.

<sup>94</sup> David DeGrazia. *Human identity and bioethics*. p. 114.



problematic separation does occur this would surely derogate the value of the advance euthanasia directive, for it is deemed to be unacceptable that the request of one person would lead to the death of someone else. The theories on personal identity that have been discussed throughout this chapter each provide a different outlook on this problem.

The most prevailing interpretation of this problem is in line with Locke's psychological approach of personal identity, and a charitable interpretation of this theory indeed manifests this fracture in identity over time. It is apparent that one no longer possesses a complex form of consciousness in this context; one's mental features get disrupted due to his suffering from dementia. The person who originally composed an advance directive changes into different incompetent person; it is as if he invisibly dies<sup>95</sup> while someone else comes into existence. If this theory would be correct then the change in identity would make it impossible to adhere to the advance directive, which was essentially intended to determine the handling of the initial but not the distinct latter individual. Due to dementia X at  $t_1$  is not judged to be the same person as Y at  $t_2$  because X is not psychologically continuous with Y.

However, I take this theory to mistakenly rest on Locke's assumption that we are essentially persons, as I have described before. Just like one wasn't a person when he was a fetus he won't essentially be a person when he ends up severely demented, this doesn't threaten his continued existence as one and the same animal over time. One's biological essence remains the same throughout his lifetime and this is not affected by any psychological change that one undergoes due to his suffering from dementia. This is in line with DeGrazia's biological approach of personal identity, in which it becomes apparent that personhood only marks a specific phase in life. Following the biological approach this leads me to the conclusion that one remains the same identical being throughout life. This contrastingly implies that advance directives can be adhered to as they continue to apply to the same individual.

Nevertheless people don't only exist as mere animals, what is distinctive of a person is that he narrates his own life story. It is an inherent characteristic of a person to think of himself as persisting over time and as thinking of the different phases of life.<sup>96</sup> In contrast with the previous theories this approach is not concerned with numerical continuity over time but instead focuses on personal characteristics, values, experiences and actions and what makes these traits properly attribute to someone and hence form a part of one's identity is its accurate inclusion into one's life story. This narrative not only provides one with a sense of self and direction in the present but also provides guidance for the future. Eventually the narrative as a whole gives meaning to certain events. But the troubling thing is that demented patients gradually break away from their narrative and sometimes completely stop living in line with their life story once they become demented; they are no longer the directors of their own story. This could lead to instances in which the valuation of euthanasia that has played a prominent role throughout one's life remains unexposed once he is torn away from his storyline by the progression of dementia. This individual has remained the same biological being despite being subjected to dementia, but his qualitative characteristics seem to have changed; this patient and others alike either no longer expresses a death wish, express it less explicitly, or could even express contradictory desires.

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<sup>95</sup> David DeGrazia. *Human identity and bioethics*. p. 170.

<sup>96</sup> Marya Schechtman. *The constitution of selves*. p. 102.

This development indicates that despite physical continuity one could still qualitatively change into someone else once he is gradually torn away from his personal narrative; here the someone else problem comes into play again. Even though this is not a rupture of identity on a numerical level, and therefore seemingly not a fundamental argument against euthanizing patients suffering from dementia based on their previously composed advance directive, this line of reasoning disregards the problematizing intuition that arises on a qualitative level concerning the unusual disruption of the narrative of the patient who has broken with his storyline. The narrative approach of personal identity does not provide clarity concerning the handling of advance directives. It turns out to be problematic whether and, if so, how the advance directive that was composed in the competent phase of life should condition this demented phase of life in which one possibly expresses different interests or none at all. It is my aim to resolve if one's previous interests could have authority over one's distinct current interests. Hereto I'll consider if an appeal to the patient's precedent autonomy can resolve the handling of advance directives in the context of narrative identity.

### 3. The role of preceding autonomy in the handling of advance directives

“Ik draag mijn levenstestament al een half mensenleven bij me, en iedereen die mij een beetje kent, kan getuigen dat ik er nooit anders over gedacht kan hebben. Het is mijn fundamentele belang dat ik die laatste fase niet hoeft mee te maken, dat ik niet zo in de herinnering van mijn kleinkinderen hoeft voort te leven. Dat is niet het belang van mijn vroegere zelf, mijn zelf uit 1980 of 2008, het is in het belang van mij zelf zonder meer, van de hoofdpersoon van mijn levensverhaal van het begin tot het eind. En in die laatste fase zal ik geen ander, daaraan tegengesteld belang hebben.”<sup>97</sup>

As described earlier many people fear the suffering that is expected to accompany dementia. It is feared that if one is irreversibly subjected to dementia one hopelessly loses grip on life and all values which have played a central role throughout one's life. Composing an advance euthanasia directive is taken to be a means by which one can be spared to undergo this future process of deterioration. I take advance directives to be a means to explicitly express personal values and beliefs in order to make the central values of one's narrative accessible to outsiders, in this case not only to close relatives and friends but also one's physician. These advance directives are not only closely linked to one's narrative because anticipated future experiences can already affect one in the present but moreover the directive expresses the desired occurrence of a certain event that get its meaning from one's entire life-story. This story, in which all of one's qualitative aspects come together, as a whole gives meaning to certain events, including one's life ending. It is not merely someone at a certain moment in time who strongly values a certain future treatment, but in line with the quotation above, it is the timeless main character of one's narrative as a whole that has an interest in receiving the valued treatment. One's life-ending forms the finale of his entire life-story, but it doesn't stand on its own, a long story of values, experiences and expectations has preceded this event. This specific story ending is highly valued, as is expressed by the advance directive that forms a central part of and explicitly exposes one's life-plot. It would not only be a loss in itself if euthanasia were not to be carried out in these circumstances, in the sense that this story would be deprived of its final scene, but it would also deprive the entire preamble that led up to this last act of its value, as it retrospectively becomes a preamble that led to nothing.<sup>98</sup> If the plot fails the entire story loses its value.

As has become apparent, the someone else problem has partly been dismantled in the sense that it doesn't threaten one's continued existence as one and the same being over time. However, people don't necessarily care about existence as such but moreover care about the quality of their existence. Patients compose advance directives as a means to remain in control over the quality of their life, even in its last phases. But composing an advance directive does not guarantee that one will eventually receive the initially desired life-ending. While people persist over time, in the sense that they essentially remain the same being throughout their existence, they only narrate their own life story in the phase in which they are persons. Dementia causes one to lose his personhood and hereto one is no longer able to control the storyline. People drift away from the thread of their narrative due to the qualitative changes they undergo. Even though one has prominently valued euthanasia throughout one's life it is very well possible that his subjection to dementia brings about a shift in his valuation or even evaporates it. Once they lose grip on their values and change into

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<sup>97</sup> Govert den Hartogh. 'Het gezag van levenstestamenten', in: *De Kwestie – Praktijkboek ethiek voor de gezondheidszorg*. 's-Gravenhage : Boom Lemma, 2011. p. 278-282. Here: p. 281.

<sup>98</sup> Govert den Hartogh. 'Het gezag van levenstestamenten'. p. 280.

someone else demented patients either no longer expresses a death wish, express it less explicitly, or could even express contradictory desires. What desire should be given priority in this context, one's initial competent valuation of life-ending or his other current desires?

In the first place it'll be my aim to get some grip on this complex situation by focusing on the role of narrativity in modern day culture by shortly discussing the role and origin of death wishes at the prospect of losing one's rational capacity. Hereafter I'll discuss if an appeal to precedent autonomy can overcome the difficulties posed by the narrative approach of personal identity in the handling of advance euthanasia directives. In this context I'll focus on values that outlive one's suffering from dementia and the possible conflict with current values. This will enable me to, lastly, discuss the possibility of euthanizing demented patients based on their advance directive.

### 3.1 Approaching death and the dying

"Never before have people died as noiselessly and hygienically as today [...] and never in social conditions so much fostering solitude."<sup>99</sup>

This quotation sententiously summarizes Norbert Elias's view on society's treatment of death and the dying. I share his marvel concerning the way in which society seemingly institutionalizes life-ending and, referring to the Dutch euthanasia practice, in which individuals are given the freedom to request future treatment that is aimed to lead to their death. This current approach of death is a product of our past and is embedded in the specific traits that are predominant in modern-day culture and society. One of the characteristics of our current society is the progressive individualization of the members of society, Elias takes this to resound in death, as he writes: "the idea that one dies alone matches the accentuation in this period that one lives alone."<sup>100</sup> In order to get a more profound picture of this modern approach of death I take it to be fruitful to consider what gave rise to this ongoing individualism.

In a comprehensive discussion of literature Philip A. Mellor and Chris Schilling identified the decreasing role of religion in society as a development that gave rise to our modern perspective on death. Previously death would cause society to lose a part of itself, for the person who died was part of that community and religious communal rituals would be a means to give vent to feelings of loss and mourning. But over time the sacred rituals lost significance, initially the rise of Protestantism already brought about a shift away from the social traditions that focused on the continuation of the community and concentrated more on the interests of the individual.<sup>101</sup> The decomposition of the sacred and the process of secularization later on also became a characteristic of the enlightenment. This period gave another boost to individualization and rationalization by encouraging people to use their rationality; probably most famously phrased by Immanuel Kant in the motto: "*Sapere aude!* Have the courage to use your own understanding!"<sup>102</sup> But where religion was able to give clear

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<sup>99</sup> Norbert Elias. *The loneliness of the dying*. New York : Continuum, 2001. p. 85.

<sup>100</sup> Norbert Elias. *The loneliness of the dying*. p. 60.

<sup>101</sup> Philip A. Mellor & Chris Schilling. 'Modernity, Self-Identity and the Sequestration of Death', in: *Sociology*, volume 27, issue 3, 1993. pp. 411-431. Here: p. 416.

<sup>102</sup> Immanuel Kant. 'An Answer to the Question: What is Enlightenment?', in: James Schmidt ed., *What is Enlightenment? Eighteenth-Century Answers and Twentieth-Century Questions*, Berkely : University of California Press, 1996. pp. 58-64. Here: p. 58.

meaning to people's lives and provide guidance in handling death, the current lack of guidance led people to undergo individual struggles in searching for meaning in both their life in general and in handling death:

"Modernity had developed alongside an extensive desacralisation of social life, yet has failed to replace religious certainties with scientific certainties. Instead, while science may have given people the possibility of increasing control over their lives (though, crucially, it has not conquered death), it fails to provide values to guide lives."<sup>103</sup>

Mellor and Schilling take this development, the focus on rationality and individuality at the expense of the sacred, to still have a profound effect on the modern approach towards death. Science has neither provided a way to overcome death nor provided general or communal meaning concerning the handling of our inevitable death; a sense of unease<sup>104</sup> surrounds the topic of death. The search for values has become an individual quest, which Mellor and Schilling take to be necessarily related to self-narratives<sup>105</sup> in which people outline their personal values that provide guidance throughout their lives. Nowadays even one's values concerning life-ending are included in these individual narratives.

I am well aware that this short overview of alterations concerning the handling of death only roughly highlights some core issues and does not do justice to the full extent of all historical developments. Nevertheless I take this trend of rationalism and individualism to be vital for the understanding of preliminary requests to die. The individual character of death invokes people to include their life-ending in their narrative, in line with the values that play a central role throughout one's life. Suffering from dementia and thus slowly losing one's rational capacity is deemed to be a doom scenario by many, this process clearly opposes rationality and values allied to it. It is suggested, as referred to by Den Hartogh, that "de negatieve waardering van dementie voortkomt uit een voor de Westerse cultuur kenmerkende overschatting van de rationele vermogens, die de alzheimerpatiënt verliest. Wat die patiënt echter zou overhouden, is de rijkdom van zijn emoties."<sup>106</sup> Den Hartogh nevertheless argues against this standpoint and emphasizes that dementia continuously confronts patients with situations which they are no longer able to grasp. While human beings naturally use their rational capacities to handle difficult situations, they now find themselves in absence of rational capacities and unable to handle these situations. Instead of broaching a diverse pallet of emotions this mainly and sometimes only evokes negative emotions, such as anger, fear and sadness. A rational way to avoid this negative burden is to formalize one's request for life-ending, as if it were a contract.

Of course, unlike a legal contract physicians are not obliged to fulfill it. The latter seems obvious, because, as has been discussed in chapter one, the request to die is very intrusive towards the physician. It is precisely because of the intrusiveness of the request that physicians often demand that it can still be reaffirmed by the patient. Advance directives "do not execute themselves"<sup>107</sup>, and actively ending another person's life goes well beyond regular medical and technical procedures. It

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<sup>103</sup> Philip A. Mellor & Chris Schilling. 'Modernity, Self-Identity and the Sequestration of Death'. p. 413.

<sup>104</sup> Philip A. Mellor & Chris Schilling. 'Modernity, Self-Identity and the Sequestration of Death'. p. 416.

<sup>105</sup> Philip A. Mellor & Chris Schilling. 'Modernity, Self-Identity and the Sequestration of Death'. p. 413.

<sup>106</sup> Govert den Hartogh. 'Dementie kan ondraaglijk zijn'.

<sup>107</sup> Cees Hertogh. 'The role of advance euthanasia directives as an aid to communication and shared decision-making in dementia', in: *Journal of Medical Ethics*, volume 35, issue 2, 2009. pp. 100-103. Here: p. 103.

forces physicians to overcome a threshold which not every physician is willing or able to do, and even when physicians participate they can still feel burdened because of the mere fact that they actively end someone's life. In any different circumstances the killing of another would be deemed to be morally objectionable, as the loss of one's life is the most definite loss one can suffer. This makes it understandable that Govert den Hartogh doesn't simply refer to this practice of euthanasia in the context of dementia as a simple medical exception on the prohibition to kill another human, but moreover as a conflict of duties in which the duty to prevent further suffering of the patient could ultimately weigh the heaviest.<sup>108</sup> The burden inflicted on the physician by the patient's preliminary request to die opposes the patient's burden that led him to compose it at the prospect of losing his rational capacity.

### **3.2 The progression of dementia and precedent autonomy**

I take advance directives to have a formal, substantive and transcendental condition. Its formal condition refers to its most basic form, it being written down by the patient or being transferred to others in some other form, like, for instance, clear reports of discussions with the patient. Its substantive condition refers to the actual content of the directive, the message it expresses; in this case someone wants to be euthanized if he comes to suffer severely from dementia, which is expected to be unbearable. Lastly, the transcendental condition of an advance directive is its most absolute condition; it ought to be a competent expression. As has been discussed before, patients are generally taken to lack competence once they come to suffer from severe dementia. If advance directives are valued in the way as was legally intended this doesn't form a problem, physicians are allowed to act on the precedent competence and proceed to euthanize the now demented patient. These directives are however rarely treated as extensions of decision-making authority of formerly competent patients, as it has become evident that physicians strongly value the patient's reaffirmation of his request to die before taking action. In line with the narrative approach of personal identity, I take one's request to be euthanized to be prominently valued throughout one's life. This is supported by one's activity of formally composing the directive and thereby revealing a substantive value to the outside world. But when one slowly breaks away from his narrative due to his suffering from dementia and qualitatively changes into someone else, it is unclear how one's initial directive should be handled. Can an appeal to precedent autonomy overcome the difficulties posed by the narrative approach of personal identity in the handling of advance euthanasia directives? In order to provide an answer to this question I'll firstly focus on fundamental interests that outlive a patient's subjection to dementia from the perspective of both Allen Buchanan and Ronald Dworkin. Hereafter I'll discuss Agnieszka Jaworska's approach of precedent autonomy in contrast with her conception of demented patient's present values.

Demented patients don't go out of existence once they are subjected to their illness; the predetermined directive remains applicable precisely because one continues to exist. These patients are still alive even though they are gradually no longer able to oversee their life-story. Buchanan argues that this change does not challenge the authority of advance directives in the sense that the non-person's previous central request to be euthanized is also one's surviving interest. He interprets this surviving interest to centrally be a means for someone to control what happens to his body after

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<sup>108</sup> Govert den Hartogh. 'Het gezag van levenstestamenten'. p. 282.

losing personhood: “Just as the interest in the treatment of one’s corpse is a legitimate interest of persons, so is one’s interest in what happens to one’s living remains.”<sup>109</sup> Buchanan takes the eventual fulfillment of these surviving interests to depend on actions that occur after the author of the directive no longer exists as a person. I interpret this to mean that one could still adhere to these so-called surviving interests when a patient is severely demented, and indeed Buchanan states that this interest can ensure the antedated death of the patient.<sup>110</sup>

This perspective on advance directives however presents a somewhat limited account of a patient’s interests, which don’t necessarily concern the treatment of one’s body. It is not so much the prospect of the undesired handling of one’s living bodily remains that causes people to compose an advance directive, but moreover the fear of the demolition of their fundamental values along with their personhood: “de afbraak van je persoon, de ontkenning van alles waar je voor gestaan hebt, het verlies van de activiteiten en relaties die je leven zin gaven. Zo wil je niet zijn, en zo wil je ook niet door anderen worden gezien.”<sup>111</sup> Additionally Buchanan leaves a patient’s potential current desires largely out of the picture. While he does emphasize that demented individuals have the capacity to experience pleasure and pain and therefore have some present interests, he nevertheless doesn’t consider the conflict between one’s surviving and present interests to be morally troublesome. A patient suffering from dementia in a late state is characterized as someone who “not only has radically truncated interests, but also has a very limited life expectancy and typically suffers a number of serious and often painful physical ailments as well”<sup>112</sup>. This negative approach leaves us with little obligations<sup>113</sup> towards the demented person’s remains, instead one’s previous interests should predominate his current treatment according to Buchanan: “the advance directive is applicable and does override whatever extremely limited obligations we may have to sustain the life of the surviving individual in such cases”<sup>114</sup>. One’s previous request for euthanasia overrides one’s current interests.

Dworkin argues that a patient’s previous values outlive the process of deterioration by appealing to one’s precedent autonomy. This calls upon the conviction that the central life values of competent and autonomous people, who determine their own life path in the present and act in a way that they themselves believe to be in their best interest, should still resound as precedent autonomy in their surviving interests after they have been subjected to dementia. Dworkin provides a more balanced view of demented patients and recognizes them to have some current interests; these are related to current pleasurable or painful experiences as these patients are able to enjoy or despise actions or events at this current moment, but he denies that demented patients have the ability to develop critical interests. He takes critical interests to have a more timeless character and to be related one’s fundamental values, such as the wish to be granted euthanasia if one comes to suffer from what one conceives to be an unbearable form of dementia. These critical interests play a leading role in one’s overarching life narrative as a whole. While the former interests solely matter if one still possesses a

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<sup>109</sup> Allen Buchanan. 'Advance Directives and the Personal Identity Problem', in: *Philosophy and Public Affairs*, volume 17, issue 4, 1988. pp. 277-302. Here: p. 287.

<sup>110</sup> Allen Buchanan. 'Advance Directives and the Personal Identity Problem'. p. 287.

<sup>111</sup> Govert den Hartogh. 'Dementie kan ondraaglijk zijn'.

<sup>112</sup> Allen Buchanan. 'Advance Directives and the Personal Identity Problem'. p. 299.

<sup>113</sup> Buchanan emphasizes that we do have an obligation to minimize their physical pain and to provide comfort. (See: Allen Buchanan. 'Advance Directives and the Personal Identity Problem'. p. 299.)

<sup>114</sup> Allen Buchanan. 'Advance Directives and the Personal Identity Problem'. p. 287.

certain awareness of the events in the present, the latter interests can be fulfilled regardless of whether the patient is aware of it, according to Dworkin. When referring to severely demented Margo, who happily enjoys her day-to-day experiences, but signed an advance directive while she was still competent, he insists that her critical interests concerning life-ending should be prioritized over her experiential interests:

“Of course, there is a conflict between Margo’s precedent autonomy and her contemporary experiential interests if she is still enjoying her life, but there is no conflict with her critical interests as she herself conceived them when she was competent to do so. If I decide, when I am competent, that it would be best for me not to remain alive in a seriously and permanently demented state, then a fiduciary could contradict me only by exercising an unacceptable form of moral paternalism.”<sup>115</sup>

Dworkin rejects the perception that Margo still enjoys quality of life through the fulfillment of her experiential interests, as this fundamentally opposes her critical interests that would most adequately suit her narrative. One’s narrative covers the values that have played a central and characteristic role throughout one’s life and when considering a patient’s treatment his life, as a whole, should serve as a background for making decisions about his treatment, not merely this last phase. It is in the demented patient’s critical interest to not continue to live because this would affect the character of his life as a whole.<sup>116</sup> In contrast with the previous view on surviving interests, this conception on critical interests leaves open the content of these central values. In contrast with Buchanan’s approach, and as was already emphasized before, I don’t take the safeguarding of one’s bodily remains to be the most fundamental value that underlies the requested life-ending. Moreover, they want to conserve their current image and take it to be of fundamental importance not to be remembered in the same way as they themselves perceive those who suffer from dementia. They wish to be spared themselves the process, and their relatives the recollection, of progressive deterioration. Dworkin’s view is open to this interpretation; this central value can outlive one throughout his deterioration caused by dementia.

Both previous views agree on the conviction that some qualitative values of a person extend into the future and that advance directives should be adhered to. The feebleness of both conceptions however lies in their disregarding of the current interests of patients. From this perspective the previously composed autonomous directive is given a dominant voice. Earlier on it has however become apparent that dementia does not appear overnight and only gradually manifests itself, this also implies that one’s interests don’t disappear at the onset of dementia and only gradually decrease throughout the different stages of one’s disease. While in the previous conceptions the autonomy and values of patients seemingly disappeared at the onset of dementia Agnieszka Jaworska argues that the current interests of demented patients should still be taken seriously as they reveal a degree of autonomy in the patient. They may still propagate and develop certain values according to Jaworska because, even though dementia causes them to lose the thread of their narrative, they may still believe to correctly want something of which the fulfillment is related to one’s sense of self-worth, and achieving this is deemed to be most important.<sup>117</sup> She takes this ability to value certain things to be equivalent to Dworkin’s conception of developing critical interest and

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<sup>115</sup> Ronald Dworkin. *Life’s Dominion : An Argument About Abortion, Euthanasia, and Individual Freedom*. New York : Vintage Books, 1994. p. 231.

<sup>116</sup> Ronald Dworkin. *Life’s Dominion*. p. 230.

<sup>117</sup> Agnieszka Jaworska. 'Respecting the Margins of Agency: Alzheimer’s Patients and the Capacity to Value', in: *Philosophy & Public Affairs*, volume 28, issue 2, 1999. pp. 105-138. Here: p. 116.



thus takes him to misjudge the ability of demented patients, at least until the stage in which they become severely demented. Due to the effect of dementia on patients it is inevitable that their current values concern what might be considered simpler pleasures: “after developing Alzheimer’s, even former highbrow intellectuals come to value, or value more highly, the pleasures of listening to music, gardening, yoga, simple art-making, telling fanciful stories to their grandchildren, or the like.”<sup>118</sup> Patients are not superficially inclined to participate in these activities but still have some rational motivation to do so and thus truly value them even though they might not match earlier values. Patients don’t acutely lose all former values at the onset of dementia; the complete set of values one adheres to might nevertheless become more limited. The persistence of some former values and the ability to propagate current interests indicates a degree of autonomy in the patient, and as long as this demented patient still expresses values Jaworska takes it to be a mistake to override these by preceding directives<sup>119</sup>. What is good for this patient is not the fulfillment of his predetermined request for euthanasia if this directive is in conflict with his current interests. Patients still have authority over their well-being as long as they still have the capacity to value.

Even though the patient’s ability to form new values is compromised due to his suffering from dementia it is important to note that dementia doesn’t cause one to lose all of his values all at once. But as some of the earlier values are lost “the exact content and the importance of the remaining values are typically reconfigured”<sup>120</sup> in the present. This imaginably could lead to instances in which people who have valued euthanasia throughout their life no longer attach worth to this anymore as this value might have slipped out of their storyline due to their suffering from dementia. These people instead have rearranged and come to value other things. The contrary could also occur, as Jaworska describes the transformation of Mr. O’Connor who had always had a very close relationship with his wife and been a very religious man throughout his life. From his religious perspective he has always strongly opposed euthanasia. Due to his suffering from dementia his religious beliefs were however not available to him anymore but he remained to be strongly attached to his close relationship with his wife. After she was gone he propagated his wish to die, which makes perfect sense given his current limited set of values.<sup>121</sup> In the light of his current values Mr. O’Connor autonomously took it to be in his best interest to have his life ended, even though this is in contrast with his previously expressed values. Furthermore it could also be very well possible that patients continue to adhere to the same value that they expressed in their advance directive; in this case there is no conflict between past and present values.

Jaworska nevertheless also recognizes that there will come a moment in which demented patients will lose their capacity to value; in the last phase of dementia patients no longer hold any values. Once one becomes severely demented he has no current values anymore and any potential conflict with past values disappears. From this point onwards she emphasizes that the treatment of patients should be “analogous to that of other terminally ill, unresponsive, physically incapacitated and suffering patients, for whom the question whether to end or prolong a life may seem appropriate. More often than not, these patients are not capable of expressing their current preferences, so conflicts between their current and former preferences do not arise.”<sup>122</sup> From this perspective

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<sup>118</sup> Agnieszka Jaworska. 'Respecting the Margins of Agency'. p. 120.

<sup>119</sup> Agnieszka Jaworska. 'Respecting the Margins of Agency'. p. 125.

<sup>120</sup> Agnieszka Jaworska. 'Respecting the Margins of Agency'. p. 124.

<sup>121</sup> Agnieszka Jaworska. 'Respecting the Margins of Agency'. p. 124.

<sup>122</sup> Agnieszka Jaworska. 'Respecting the Margins of Agency'. pp. 134-135.

advance directives are not given any power over patients for as long as they still hold values which give them authority over their lives. Only in the final stages of dementia, in which one's capacity to value has disappeared, the advance directives that expresses a patient's valuation of euthanasia can be adhered to because this is in the best interest of the incompetent patient. Severely demented patients have lost their autonomy and no longer hold and express values, and Jaworska takes it to be in their best interest to privilege their previous values in this instance.<sup>123</sup> I'll come back to this later on.

### 3.3 Euthanasia based on an advance directive

It has been my aim to examine the moral acceptability of euthanizing patients suffering from dementia based on their advance directive. In this context I have not merely focused on the essential biologically numerical continuity of people over time, but, as persons distinctively narrate their own life-stories, I have also focused on narrative identity. These life-narratives are taken to comprehend personal characteristics and values which give meaning to one's entire life, and it is thus hoped that these values will still guide one's future. In this regard I have taken advance directives to be a means to explicitly express personal values and beliefs in order to make one's narrative accessible to outsiders. Formally the predetermined directive remains applicable over time precisely because one continues to exist as the same being over time. But as demented patients gradually break away from their narrative, others are burdened with the directorship over the storyline of the life of another and find themselves confronted with the intrusive request for life-ending. Even though patients don't go out of existence at the onset of dementia they don't remain the person they were either, sometimes one's request for life-ending has evaporated completely, it is expressed less explicitly, or one could even express contradictory desires.

Both Buchanan and Dworkin have suggested that some fundamental interests, such as one's deep-seated desire for life ending, outlive one's deterioration due to dementia. Though this is a comprehensible statement, I am inclined to state that this only applies to those cases of severe dementia in which one is completely torn away from his life story. Personhood and severe dementia only depict two extremes, the grey area of dementia in which one partly identifies with his narrative and rearranged old values has not been thoroughly taken into account in this view. In his writings Den Hartogh outlines a picture of his future demented self who is happily enjoying the sun<sup>124</sup>, in line with Jaworska's conception it could be said that this indicates that this man still adheres to certain values in life. While the earlier theories of Buchanan and Dworkin would suggest that one's advance request for euthanasia can still be fulfilled regardless of whether the patient still is aware of his past values and despite his current values, I agree with Jaworska that the current degree of autonomy of a patient deserves to be respected. One's current interest shouldn't be overridden by a past request, even though this request is in line with the values that have played a central role throughout one's life-narrative.

On the one hand this indicates that if a patient still propagates his values for life-ending in his current state of suffering this can be deemed the reaffirmation that physicians long for in order to

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<sup>123</sup> Agnieszka Jaworska. 'Respecting the Margins of Agency'. p. 112.

<sup>124</sup> Govert den Hartogh. 'Het gezag van levenstestamenten'. p. 282.

euthanatize a patient. But on the other hand this also implies that if a patient who wandered off from the thread of his life story, and currently seems to be concerned with different values, physicians ought not to take his life even though this desire was previously expressed. Furthermore, it indicates that patients whose values have been rearranged due to their suffering from dementia and have now come to value euthanasia, like Mr. O'Connor in the writings of Jaworska, but did not compose an advance directive in the past, are still eligible for euthanasia. And, when turning back to suffering from severe dementia, this indicates that in a phase of life in which one has completely torn loose from his previous story-line but also stopped having present interests due to the loss of his autonomy there no longer exists a conflict between one's previous request and one's present condition. In these circumstances one's advance directives can determine his current treatment: the ending of his life. In this latter circumstance death is no longer an evil<sup>125</sup> for all that has remained of a person is his body.<sup>126</sup>

One's precedent autonomy proves to provide guidance in certain circumstances but does not necessarily determine one's treatment in the present. One's suffering from dementia could very well cause one to lose the thread of his narrative as a whole even though one is not instantly torn away from the entire storyline. Moreover the demented patient initially shifts to a sidetrack of his storyline as he remains to have the capacity to value throughout the progression of his disease. This could imply that a patient continues to express his request for euthanasia in line with his advance directive; in this case this request can be adhered to. But a patient might also lose sight of this value in the sense that he no longer refers to euthanasia and is now preoccupied with different values. In this case the advance directive shouldn't be adhered to, for this would disregard his current autonomy even though this diverges from the storyline of his narrative. In the context of dementia in a late state, when patients no longer express any values<sup>127</sup>, and thus the possible conflicts between their advance directive and present interests have completely disappeared, one's advance directive can be adhered to as this is in line with his preceding autonomous values concerning his life-ending. In the context of the narrative approach of personal identity, and in grave contrast with current practice, I hold it to be morally permissible in the latter circumstances for demented patients to be euthanized based on their advance request for euthanasia.

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<sup>125</sup> Govert den Hartogh. 'Het gezag van levenstestamenten'. p. 281.

<sup>126</sup> I take the case of Mrs. Joukje van der Enden to serve an illustrative role in this context, as her husband Kees van der Enden declared: "Ze is weg. Want dat is het natuurlijk, ze is weg. Ze is niet dood, maar ze is weg." (In: 'Als ik dement ben, wil ik dood', Zembla. 02:28-02:34min.) Mrs. Van der Enden still existed as such, her body continued to exist, but all of her qualitative characteristics had evaporated.

<sup>127</sup> I'm well aware that the capacity to value is not an unequivocal notion, but in the context of dementia I take this capacity to be associated with the ability to actively value certain experiences. Furthermore I take a severely demented patient to be a "persoon die eigenlijk alle persoonskenmerken heeft verloren en alleen nog passief enkele, hopelijk niet al te onaangename ervaringen ondergaat." (in: Govert den Hartogh. 'Dementie kan ondraaglijk zijn'.) These patients no longer value anything but merely passively undergo moments in time.

## Conclusion

With the legal possibility for euthanasia at hand, people who possess an advance euthanasia directive regularly take their directive to secure their future medical treatment in case they come to suffer from dementia. Physicians however hardly adhere to these intrusive directives in practice; they regularly take it to be morally troublesome to euthanize patients suffering from dementia based on a predetermined directive. Especially the fear that patients change into a completely different incompetent someone else, which could derogate the value of their directives, has turned out to be ubiquitous. It has been my aim to answer the question of whether it is morally acceptable to euthanize patients suffering from dementia based on their advance directive in the light of the someone else problem.

The prevailing interpretation of this problem is rooted in the psychological approach of personal identity. A charitable interpretation of this theory manifests a fracture in a person's identity over time; consciousness gets ruptured due to their illness. Nevertheless, this theory turned out to mistakenly rest on the assumption that people are essentially persons. Instead, in line with the biological approach of identity, it becomes apparent that one's biological essence remains the same throughout his lifetime. His suffering from dementia does not threaten his existence as one and the same being over time. One thus does not numerically turn into someone else; he remains the same identical being throughout existence. However, people don't necessarily care about existence as such but moreover care about the quality of their existence. In this respect it becomes apparent that people don't only exist as mere animals, but what is distinctive of a person is that he individually narrates his own life story. Even though the biological approach resolved the someone else problem in the sense that advance directives can be adhered to as they continue to apply to the same individual, the narrative approach indicates that one could still qualitatively change into someone else once he is gradually torn away from his personal narrative, due to his suffering from dementia, and loses control over his storyline. This implicates that there is a someone else problem on a qualitative level that constrains the process of euthanizing demented patients based on an advance directive.

Hereto I have considered if an appeal to precedent autonomy can resolve the handling of advance directives in the context of narrative identity. I have taken advance directives to be a means to make one's central valuation of euthanasia accessible to outsiders. Even though patients gradually lose the thread of their narrative due to their suffering from dementia, they don't immediately lose grip on all values that have played a central role throughout one's life. Moreover I take the demented patient to initially shift to a sidetrack of his storyline as he remains to have the capacity to value; this latter ability indicates that there is a degree of autonomy present in the current patient. This patient can still hold values throughout the development of his illness, even though this might be a rearranged selection of one's past values. An unconditional appeal to one's precedent autonomy completely disregards these present values. One's current interests ought not to be overridden by a predetermined directive, even though this directive has played a central role throughout one's life-narrative.

As the current interests of this qualitatively changed individual restrict the handling of advance euthanasia directives I must conclude that the someone else problem impedes the euthanizing of demented patients based on an advance directive. If a patient has lost sight of his valuation of

euthanasia and is now concerned with different interests, he has qualitatively changed in such a way that it would disregard his present autonomy if his past directive would be adhered to. Nevertheless, it could also very well be possible that a patient continues to express his request for euthanasia in line with his advance directive; in this case this continuous request can be adhered to. Furthermore, when suffering from dementia in a late state patients no longer express values anymore. At that moment their present interests have completely evaporated and so has the conflict with one's precedent autonomy, which was expressed in their advance directive. The someone else problem has disappeared in this context. At this moment one's advance directive can be adhered to<sup>128</sup> as this is in line with his preceding autonomous values concerning his life-ending. I hold it to be morally permissible in the latter circumstances for advance directives to replace a current request and for euthanasia to be possibly carried out based on a demented patient's advance euthanasia directive.

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<sup>128</sup> I am well aware that patients, in line with the requirements of due care, must suffer unbearably in the present in order to be eligible for euthanasia. It is argued that severely demented patients don't undergo suffering in the end stages of their disease, as referred to by Den Hartogh : "dat tekenen van zulk lijden [bij gevorderde dementia] in de praktijk niet worden waargenomen" (in: Govert den Hartogh. 'Dementie kan ondraaglijk zijn'). I'm however not convinced that patients can no longer express suffering at this point; even in the phase of life in which patients have lost the capacity to value they can still show signs of bodily unrest which could very well give an indication of their suffering.

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## Euthanasieverzoek

*Lees voordat u deze verklaring invult de toelichting bij het euthanasieverzoek.*

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Naam

Geboortedatum

Geboorteplaats

Lidnummer

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Voor het geval ik mijn wensen op medisch gebied niet meer kan aangeven, richt ik mij met deze verklaring tot iedereen die bij mijn medische behandeling of verzorging betrokken zal zijn.

Mijn vertegenwoordiger zal dit euthanasieverzoek, zodra dit aan de orde is, onder de aandacht brengen van mijn behandelend arts.

### 1. Uitgangspunten

Wanneer ik in een toestand kom te verkeren waarin ik uitzichtloos en ondraaglijk lijd, bijvoorbeeld doordat:

- er geen redelijk uitzicht bestaat op terugkeer naar een voor mij waardige levensstaat,
  - en/of
  - mijn verdergaande ontluistering te voorzien is,
- wil ik dat mijn arts mij de middelen toedient of verstrekt om mijn leven te beëindigen.

### 2. Persoonlijke aanvulling (niet verplicht)

*Lees hiervoor ook de toelichting*

Ter aanvulling geef ik hierbij een persoonlijke beschrijving van wat ik zie als uitzichtloos en ondraaglijk lijden.

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*Zie ommezijde*

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<sup>129</sup> NVVE. *Toelichting bij de wilsverklaringen*. Amsterdam : 2013, 9<sup>th</sup> revised edition. pp. 28-30.

### 3. Verzoek tot euthanasie

Als ik kom te verkeren in een toestand van uitzichtloos en ondraaglijk lijden verzoek ik mijn arts uitdrukkelijk mij de middelen toe te dienen of te verstrekken om mijn leven te beëindigen.

### 4. Risicoaanvaarding

Deze wilsverklaring blijft van kracht, ongeacht de tijd die is verstreken sinds de ondertekening ervan.

Het is mij volkomen duidelijk dat ik deze wilsverklaring op elk moment kan herroepen. Ik aanvaard bewust de mogelijkheid dat een arts, als ik op enig moment niet meer in staat zou zijn zelf mijn wil kenbaar te maken, gehoor geeft aan dit euthanasieverzoek, ook als ik daar bij actueel bewustzijn anders over zou zijn gaan denken.

### 5. Geldigheid van de wilsverklaring

Deze wilsverklaring heeft rechtskracht en geldt uitdrukkelijk als een geldige en door de wet\* erkende schriftelijke verklaring van mij voor het geval ik later door welke oorzaak dan ook niet meer kan beslissen over mijn medische situatie zoals bedoeld in deze verklaring.

### 6. Ondertekening

Ik heb deze wilsverklaring zorgvuldig overwogen, ik heb mij daarover goed geïnformeerd en ik ben op het moment van ondertekening in het bezit van mijn volle verstandelijke vermogens. Door dit euthanasieverzoek te ondertekenen herroep ik alle eventuele eerder door mij ondertekende soortgelijke verklaringen.

Datum

Plaats

Handtekening

\* Basis van het euthanasieverzoek in de wet:

Artikel 2 lid 2 van de Wet Toetsing Levensbeëindiging op verzoek en hulp bij zelfdoding:  
*Indien de patiënt van zestien jaren of ouder niet langer in staat is zijn wil te uiten, maar voordat hij in die staat geraakte tot een redelijke waardering van zijn belangen terzake in staat werd geacht, en een schriftelijke verklaring, inhoudende een verzoek om levensbeëindiging, heeft afgelegd, dan kan de arts aan dit verzoek gevolg geven. De zorgvuldigheidseisen, bedoeld in het eerste lid, zijn van overeenkomstige toepassing.*

[illegible]

Ik heb deze wens tot euthanasie bij dementie zorgvuldig overwogen, ik heb mij daarover goed geïnformeerd en ik ben op het moment van ondertekening in het bezit van mijn volle verstandelijke vermogens.

Handtekening

