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## **On Reminding and Forgetting: Care about Moral Responses in the Case of Alzheimer's Disease**

**Abstract:** In this article, caring, remembering and sharing memory are presented as moral responses, the case study being Alzheimer's disease (AD). Memory connects memories and images, while care connects individuals, which is an ethical issue. When a person's memory is lost, the care of others becomes the only thread connecting them to the world. AD deprives a person of memories, body control, makes it impossible to remember, communicate, move, recognize the environment, and disrupts consciousness. Caring for a patient with a neurodegenerative brain disease requires constant reminding and reiteration; the presence of a caring person reminds of what the patient themselves can no longer remember. Lost memories do not mean that life or relational values have also lost their meaning. The description of the memory movement emphasizes the importance of repetition in the moral act. Highlighting the matter of care, also in scientific work, is the aim of this text. To care is to remember, on behalf of the AD patient, about the patient's life. Within bioethical research, moral responses are an important point for projects which seek to improve the condition of patients—not only the condition of health but also the comfort of life. This improvement will not be possible without attentive, committed caregivers and their responsible attitude in the face of the phenomenon of memory loss.

**Keywords:** Alzheimer's disease, memory, care, moral response, ethics, bioethics

## Remembering and Moral Responding: Square One

How do we understand a *moral response*, when the need of being cared for cannot be expressed—because of memory loss? Patients with Alzheimer’s disease are not able to remember much, but still are a part of the common narration about morality: not just as responsibility but also as individual liabilities. Here, the presence of caregivers makes moral responses more adequate to the needs of caring and being cared for. They witness the loss and the burden of forgetting, they care for life that is left by reminding about its importance—because of the shared memory, common and personal. Why is memory so relevant? We often forget about the moral aspects (including the moral aspect of memory) when it comes to interpreting medical issues. By concentrating on the matter of care and considering how bioethics and phenomenology try to answer questions about moral acts—in this paper: the moral acts concerning AD patients—we are closer to the accurate interpretation of the attitudes adopted in medical practice. The definition of ethics and morality should represent openness characterized by the contemporary tendency of researchers and medical specialists to focus on an individual patient, thus building the dialogue every time when it is needed. Because memory holds individual memories, the interpretation of what is morally right may differ from the ones we know and accept; the dialogue does not mean that we have to accept—it means that we have to decide, and sometimes we need to decide what is good in the name of someone else, in the name of a different, concrete life-world. Not every right act can be predicted by a theoretical model. In bioethics we should not appeal only to theory and its principles, especially given that, while the discipline is “young,” bioethical problems are much “older” than we may think. And thinking includes the process of remembering what we have been taught in the past and what we have missed. In medicine we should not miss anything, or, at least, miss as little as possible. Without memory, we do not own any memories and we cannot share any of them. *Caring* means *remembering*. To embody and to realize the relational values, presence matters enough to make a difference to people who are facing the ultimate occurrences—such that occur near the end of life. Before we analyze the situation of AD patients, let us present the interpretation of memory and its movements.

From the first memory to the last one, personal memory holds the interval in between. Individual memory comprises the cause and the source of memories, but it is not the source itself; not when it comes to analyzing the meaning of moral values. In this article we will use the term of relational value, whose meaning is the same as ethical and moral values. Memories are not the source of events, but they affect our experiences and interpretations. The ensuing image is internal and intersubjective: on the one hand, private and inward, and on the other hand, concerted and mutual. Is it also moral? Because of the individual design of remembrance we may speak of the layers of each image. This makes preserving relational values a repeated movement, made possible by our ability to remember, our care to experience values and letting other people experience values in their own way. Repeating does not mean that moral responses are always the same. Moral acts might always be difficult in the same way, but people, their conditions and circumstances may change. Per-

sonal interpretation follows the memory, which due to conscience, can be essential to evince these values, intrinsic and shared. Chosen values decide about the moral response, the narrative weft and cognition; without the memory and its movement of importance, of making things meaningful to us, the human ability to make things happen, to become present for others is not possible.

This text highlights the dependency of the individual memory of the AD patient, when they must depend on others, on their memory, moral acts and ability to care. In ethical and bioethical research the meaning of what is universally valid because of personal, moral responses, acts of authentic care, helps to create bioethical projects, open for a responsive, interdisciplinary dialogue. In this dialogue we should ask about our ability to protect people and their values—why do we care?; are we able to protect them?; is a particular moral response right? Responses *to* and *toward* other people are indicated as important, relevant for ethics and preserved for human (and non-human) relations, that is, morality. While responding, we answer to relational values, the same we know due to other people. Thus being moral is to endeavor values, to make them present and to preserve them in relations, and also, to live them through. Necessary, if insufficient, for this individual dependence and moral response, is an efficient memory. The reason *why* time is valuable established memory as the individual record of personal life, not only on the ground of its temporal character. Every memory is temporary but none can be repeated. It is because of the meaning underlying each answer to the question: “what is important to you?,”<sup>1</sup> asked when the patient is able to express their will, sometimes the last one. Not the matter of memory itself, but its motion of drawing out the intrinsic sense, and, going further—intersubjective sense, points to something that was always present, worth *reminding*. *Forgetting* is the other side of the same phenomenon, often noticed at risk of losing the sense of one’s own importance, frequently observed in many cases of diseases.<sup>2</sup> Thus *importance* is the repeated, ethical motion following memory, and so remembering, among others, is the ability to bring out the significance and to recognize the most compelling relational values—the ones that reveal the sense of moral responses and individually complete the shared world.

The main thesis of this article is that *memory has made it possible to pass on relational values, from one person to the other*. In the cases of AD, when forgetting replaces remembering, the caregivers realize the relational values in caring for their patients. How do we know about relational values? Memory has made it possible to pass on relational values, because people before us received and accepted the

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<sup>1</sup> All fragments of the dialogues come from interviews and personal conversations with patients, ill persons and medical staff in years 2015–2022. My philosophical research is focused on *dignity* and my own project of reflective bioethics, mainly in the context of palliative and terminal care.

<sup>2</sup> Analyses will include mainly examples of neurodegenerative brain diseases, like vascular dementia or Alzheimer’s disease. For further reading, see the original work by A. Alzheimer, “Über eine eigenartige Erkrankung der Hirnrinde,” *Allgemeine Zeitschrift für Psychiatrie und Psychisch-gerichtliche Medizin* 65 (1907), pp. 146–148. See also: D.B. Teplow, M. Yang, R. Roychaudhuri, “The Amyloid  $\beta$ -Protein and Alzheimer’s Disease,” chapter 1, [in:] *Alzheimer’s Disease: Targets for New Clinical Diagnostic and Therapeutic Strategies*, R.D. Wegryzn, A.S. Rudolph (eds.), Boca Raton 2012, pp. 1–85.

values, which were already completed by the act of acceptance. To accept is to vary and verify in the first place. From one generation to another, we inherit this movement to *pass on*, also with the mark of *passing*, of being temporary. What makes collective memory possible is the individual memory. Someone remembered before, so we can remember now, the memory remains as the difference—between what is worth remembering and what is worth reminding. We experience values in interpersonal relations. In other words, the interpersonal relation is the place to experience values, ethical and moral as well. That is why we can use the term of relational values. Being in the relation, giving the other person a chance to experience our care, is moving towards them, because it is the person who conceals and carries the human memory. When the person forgets about their own importance, their own life, the responsibility lies on someone who can share the values to provide and carry the memory as a moral response. It has an impact on the way how we care about people who are still a part of the shared world, despite their memory loss. Due to ethics and axiology, we already know about the mutual character of any human relation. We may be immersed in solitude, but also in unity with others, we experience distinctiveness, and we understand what is accordance. The relation with the world—with others—is not about to break off with the moment of memory loss, only the recognition and its continuity is torn. Since human values are shared, memory becomes shared as well, even of those who can no longer maintain it. Here, being familiar with the world does not indicate knowledge about its encountered objects and laws—it indicates being familiar with other people, in the entanglement of relations.<sup>3</sup>

Memory is necessary for the moral response, since it (1) is the ground for mental operations like deciding, correlating or evaluating (in the sense of Latin *pretium*, *aestimo*, that is, to assess the meaning). It is the space to coordinate reasoning and intuitive thinking, (2) is compelling for imagination and prescience, (3) holds personal reasons *why* we choose one value instead of another, thus choosing reasons to individually complete the shared world with relational values—reasons as memories, and (4) unveils the matter of importance. Like we have said before, *importance* is the repeated act of the memory, the ability to bring out the significance and also to void, to name what is insignificant in moral responses. But to understand the relevance of memory in ethics and its role in moral acts, we need further questions, and we are about to give examples from the ethical and bioethical context. Thus even memory that is not working properly, like in dementia, is still a memory of a person, with the exceptional personality, experience, patterns, and reasons. The analysis in this article concentrates on points (3) and (4). Answering *how* we choose values may be in the range of competence of ethics, psychology or neurosciences, but for sure is in the cognizance of care. Whereas asking *why* belongs to the competence of philosophy. Philosophical, ethical thinking is caring

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<sup>3</sup> I am not the author of the term “entanglement.” Relations were always explicit in my research, but I owe the concept of “entanglement” to many conversations with M. Kostyszak. To know her latest publication, see M. Kostyszak, *Personal Ethics: On the Transforming Potential of Art and Technology*, Warszawa 2019.

to ask the right questions, to solve a problem or to redefine our understanding of the issue. Can we be good researchers when we do not care? About the results of our research, about the lives the research affects, about the way how our narration helps to “reach” ethical and moral values? We seem to remember relational values better than we may explain. We remember faces, gestures, words, and motions conjoining pieces of our image of the world, with these threads we follow the values which we experience, then analyze them in context of a particular life-world. Since memories are shared, the image of the world is shared, by placing us among other people, other life-worlds, not less important but more resilient to transience.

## I. Sylphlike Motions of Memory

When did something become important, when did the difference between the relevant and the irrelevant, the valuable and the worthless become apparent, possible to be pointed out? Looking through all the accessible moments as memories, we ask *when* it was possible for their meaning to emerge? We do have memories which are less than a trifle—and we may still return to them in between the meanings, odds and ends. We remember and we forget, everything that stays and leaves our memory happens to build our identity, the way how we recognize ourselves, and also how we find others. Remembering is finding the particular memory; memorizing is keeping memories, forgetting is letting them fade.<sup>4</sup> As we are reminded, we draw out what is forgotten, but still is in the range of the memory; thus, we cannot draw out a memory which was never there. This is how happening dissociates the real from the unreal, memory from the image. Yet mental creations are characterized by a different way of existing, like geometrical figure or a hypothesis. Husserl, using the example of a lasting sound, analyzed how the immanent temporal objects appear in our consciousness,<sup>5</sup> and after that Ingarden presented the issue of existence of the musical work.<sup>6</sup> We can listen, but we cannot remember and repeat the sounds without memory, so we cannot really hear the whole musical work. Can its beauty affect us, then? Consciousness and memory allow us to observe the constancy of time and, as Bergson remarked, the changeability of varied states.<sup>7</sup> Human brain tends to transcribe everything that happens,<sup>8</sup> so we can remember a relevant moment—when someone smiled at us—silence was sublime, air scented and the touch of hands was warm and caring. Such details of various kinds prove we can describe the whole event; everything can be pictured in mind because of the perceptual and common experience. Engrams, known as memory

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<sup>4</sup> Remembering and forgetting are also mentioned by J. Blustein, *The Moral Demands of Memory*, New York 2008, pp. 19–25.

<sup>5</sup> E. Husserl, *On the Phenomenology of the Consciousness of Internal Time*, transl. J.B. Brough, Dordrecht 1991, pp. 25–26.

<sup>6</sup> See R. Ingarden, *The Work of Music and the Problem of Its Identity*, transl. A. Czerniawski, ed. J.G. Harrell, London 1986.

<sup>7</sup> H. Bergson, *Pamięć i życie*, transl. A. Szczepańska, Warszawa 2001, p. 5. French edition: *Mémoire et vie*, Paris 1965.

<sup>8</sup> For many reasons memories may not be always precise.

traces, constitute one of the brain abilities, but we possess more than just direct information. A trace leads not only to the immediate event or phenomenon, but also to the care for the presence of importance.

Care is always an ethical matter.<sup>9</sup> Caring, even if it is misdirected, affects the order of everything else and everyone around. The understanding of *what is good* and *how to do right* is often intuitive, but it is not an accusation. The contradistinction between *a priori* and *a posteriori* should be verified in each particular case, and the knowledge about *what is* and *what should be* works alike. Personal bearing defines our understanding of the good. From this point of view, the question about the memory and its motions of reminding and forgetting appears to be the question about the importance—what is important enough to stay in the individual and collective memory, and be named good or humane? Although that which is significant is always present, it needs to be reminded. In the light of caring about human meaning and human sense, we are conditioned by our knowledge and needs. Memory sorts the memories by their importance, it works like a sieve, as long as it is possible—the most important thoughts and memories stay the longest.

To understand the motions of memory, let us describe the movement itself, the image interpreted in this article: it (1) opens and closes, not in the basic sense of transcribed or faded memories, but in the sense of initiating the process of personal response. Reaction to another person and to human meanings which is thoughtful, not involuntary or reflexive, opens—*us*, (2) is settling, its subtle motion enables recognizing and being familiar, (3) finds accordance—between memories and actual events (both, *explicit* and *implicit memory*), (4) repeats the sequences while it returns to personal memories (*long-term memory*), (5) holds the pattern—like our habits (*implicit memory*). Mutuality between people is also a pattern, but it requires consideration, and thus being aware of own behavior, choices and mutual dependence, (6) sorts memories by their meaning and practical causes (*short-term memory* and *long-term memory*). Finally, there is the motion (7) towards importance which is *the motion towards the other person*. It is initial for understanding relational values. Every person and generation repeats these motions, so we can follow its continuity in our families, cultures and observe its diversity because of the mutual dependence of individual and collective memory. While conjoining one perspective with the other we may speak of a common, shared world; experiencing, remembering, and thinking enable the existence of the life-world<sup>10</sup> discussed by phenomenology and understanding the “[...] *question* to the Other and about the other”<sup>11</sup> in the philosophy of dialogue.

A lot happens in the space of consciousness that can be immediately named; reading this text is an example. For an AD patient, the process is disordered, mostly

<sup>9</sup> That is emphasized especially by care ethics, for example by N. Noddings, *Caring: The Feminine Approach to Ethics and Moral Education*, Berkeley 2013. See also, M. Uliński, *Etyka troski i jej pogranicza*, Kraków 2012.

<sup>10</sup> E. Husserl, *Crisis of European Sciences and Transcendental Philosophy: An Introduction to Phenomenological Philosophy*, transl. D. Carr, Evanston 1970, p. 48. The original term is *Lebenswelt*.

<sup>11</sup> P. Hayat, “Philosophy Between Totality and Transcendence,” [in:] E. Lévinas, *Alterity and Transcendence*, transl. M. Smith, London 1999, p. xii.

we may hear “I do not remember,” or “I do not know,” which means that the thought is lost, precluding reading, naming, or describing the moment named *now*. Memory is the constant act of bringing out images and words, feelings and thoughts, for the continuation of consciousness. Of course, under extreme conditions brain may try to protect us by blocking access to our memories of what we may read as violent—even if the intention is to protect and enable further functioning. A lot depends on the interpretation of the event. Memory keeps pleasant memories and also those that are painful and traumatic. Trauma can lock a particular memory of a hurting event, but it does not mean that this memory disappears. Disappearing is the privilege of something unimportant or ailing. Reaction to abuse can be aggressive because responding to violence allows many types of self-defense. It does not exclude the matter of free will and choices.

Diseases can be also violent, by tearing out the memoirs of the familiar. Without memory we lend ourselves to the circumstances and basic instincts. The human body repeats the reactions which are obvious, but after a while, the body gives up in the same way as memory—it is nothing exceptional in the reality of hospitals and hospices.

## II. Forgetting

“Loss precedes presence: every image must abide by this rule.”<sup>12</sup>

Alzheimer’s disease leads, among other things, to memory loss and death.<sup>13</sup> Receding memory captivates the patient in their own body which becomes unfamiliar. What does it say about the importance of memory? Let us present what happens when somebody’s memory does not function properly.

When forgetting replaces remembering, the process of reminding is disturbed not only by time and senescence. The neurodegenerative character of this disease and its three stages affects the cognitive abilities and behavior. “The most common early symptom of Alzheimer’s is difficulty remembering newly learned information because Alzheimer’s changes typically begin in the part of the brain that affects learning.”<sup>14</sup> About patients in the late stage we can read in one of the WHO’s documents: “The last stage is one of nearly total dependence and inactivity. Memory disturbances are very serious and the physical side of the disease becomes more obvious. [A.W., The patients are:]

- Usually unaware of time and place,
- Have difficulty understanding what is happening around them,
- Unable to recognize relatives, friends and familiar objects,

<sup>12</sup> R. Calasso, *Literature and the Gods*, transl. T. Parks, New York 2001, p. 76.

<sup>13</sup> B. Duthey, “Update on 2004 Background Paper, BP 6.11 Alzheimer Disease,” *Priority Medicines for Europe and the World: A Public Health Approach to Innovation*, 20.02.2013, <https://www.medbox.org/document/background-paper-611-alzheimer-disease-and-other-dementias#GO> (accessed 7.11.2022), p. 6.11–5. See also, “S.v. Alzheimer’s Disease,” [in:] C. Turkington, *The Encyclopedia of Alzheimer’s Disease*, New York 2003, p. 14.

<sup>14</sup> Alzheimer’s Association, “What Is Alzheimer’s,” <https://www.alz.org/alzheimers-dementia/what-is-alzheimers> (accessed 16.08.2020).

- Unable to eat without assistance, may have difficulty in swallowing,
- Increasing need for assisted self-care (bathing and toileting),
- May have bladder and bowel incontinence,
- Change in mobility, may be unable to walk or be confined to a wheelchair or bed,
- Behavior changes, may escalate and include aggression towards carer, nonverbal agitation (kicking, hitting, screaming or moaning),
- Unable to find his or her way around in the home.”<sup>15</sup>

There is only one thing that may be reassuring—near the end, the patient does not know what is happening, is often unconscious, unaware, and depends on others. Health care requires medical care, but not only that, as the reading further explains: “Education and support relating to ethical decision-making and human rights should be an essential part of capacity-building for all involved in providing dementia care, including policy-makers, professionals and families”.<sup>16</sup> And “[...] responsibility falls largely on unpaid informal carers, and informal care costs predominate.”<sup>17</sup> “Ethics” and “responsibility” are mentioned once and they refer to the matter of education and costs, thus statistics represent the issue approximately and the economics already leverages both. Only one term is unequivocally ethical: *care*. It appears over a hundred times in this elaboration and explains the ethical meaning of this document. It is just an example, but we see how easy it is to assume or take for granted the presence of care. However, can all patients, their families and doctors, confirm this statement? In bioethics, ethical thinking is the practical means to call things by their name. Caring does impose ethical prominence, but not for the sake of the supremacy of ethics, only out of the regard to the fact that everyone has an equational importance. In our research, statistics do not represent individual circumstances and economics do not present personal values; they always overlook something which must be not forgotten, which was also their basis not so long ago—shared purposes. Still, lone “informal carers” are the ones to remember about the real matter of care and their purpose which is yet not shared. Here, caring would mean remembering. But how close are the acts of care and memory?

The example of AD is not given only because of the issue of memory loss. While losing memory, the patient is losing the identity, life, independence, the ability to settle again. There is no chance for accordance without the presence of the familiar, relations seem strange or even hostile. The same happens with the functioning of the body. A reflex action does not hold anything more than the basic reaction to direct incentives and, after a while, even the incentives do not make a difference. Without the context ensured by memory the patient is passive. How can we speak about morality in this case? The knowledge and awareness about needed a human relation lays on the side of the caregiver, hopefully, at least one. Even when surroundings seem nameless for the patient, the caregiver must know about

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<sup>15</sup> B. Duthey, “Update on 2004 Background Paper, BP 6.11 Alzheimer Disease,” p. 6.11–7.

<sup>16</sup> *Ibidem*, p. 6.11–34.

<sup>17</sup> *Ibidem*, p. 6.11–26.



the burden of forgetting and about the liability of reminding. The last one will occur as valuable. Another reason for giving the example of AD is the issue “The Fundamental Moral Question: Do People with Dementia ‘Count?’”<sup>18</sup> Well, they do count, and not because of the work of caregivers. It is because of the importance of individuals, which we will try to justify on these pages. Although motions of memory are repeatable, the uniqueness of every individual makes personal acts worth repeating; the whole content of inward experience remains unique. Does treating persons as numbers, anonymous, nameless patients define our ability to care? Hopefully, it does not.

Without the memory we cannot expect from the patient any cogitation and the responsibility for their actions is hugely narrowed down—until it completely diminishes. The caregiver faces many challenges, from minor to major ones.

Memory difficulties may manifest themselves in other ways. Each may pose analogous ethical dilemmas. The AD patient may, for example, repeat the same question over and over again. In this situation, experts say that loved ones should not say, “You just told me that.” Rather, they should say, “That’s interesting. I didn’t know that,” even though this is a lie.<sup>19</sup>

What happens if we have repeat it each day, for few years? Let us ask, then, what is more important: the truth, which will be forgotten in few minutes, or our presence, which will be remembered the longest? Even if contact with the patient is difficult, it is important to remain as one of the last, constant components of the patient’s habitat—thus we willingly call it *home*. Alzheimer’s disease “[...] and other progressive dementias slowly but surely deteriorates the fundamental skills of communication—not only does the individual lose verbal communication abilities so that expressing personal needs and feelings becomes difficult but also the ability to understand verbal communication directed towards the individual also diminishes. This breakdown in communication is an incredibly difficult and emotionally painful loss to accept and to manage. It leads to frustration not only for the person with this awful disease but also for caregivers.”<sup>20</sup> The lack of communication may be disturbing, but the relation is based not only on verbal conversations. When the disability affects cognition, some patients

[...] may have limited or no apparent understanding of their medical condition or of the consequences of treatment decisions but may be able to express wishes and preferences concerning their lives, or these preferences may be evident to caregivers. Surrogate decision-making concerning a person with a cognitive disability must always consider how this person may experience and express pain and suffering, including suffering resulting from the inability to continue activities that give meaning and pleasure.<sup>21</sup>

<sup>18</sup> S.G. Post, “Ethical Issues: Perspective 2: The Fundamental Role of Personhood,” [in:] *Caregiving for Alzheimer’s Disease and Related Disorders: Research, Practice, Policy*, S.H. Zarit, R.C. Talley (eds.), New York 2013, pp. 154–164.

<sup>19</sup> E.G. Howe, “Ethical Issues in Diagnosing and Treating Alzheimer Disease,” *Psychiatry* (Edgmont) 3 [5] (2006) pp. 43–59, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2990623/#B30> (accessed 20.08.2020). The author refers to C.J. Strauss, *Talking to Alzheimer’s: Simple Ways to Connect When You Visit with a Family Member or Friend*, Oakland 2001.

<sup>20</sup> V. Benner Carson, K. Johnson Vanderhorst, H.G. Koenig, *Care Giving for Alzheimer’s Disease: A Compassionate Guide for Clinicians and Loved Ones*, New York 2015, p. 75.

<sup>21</sup> N. Berlinger, B. Jennings, S.M. Wolf, *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life*, New York 2013, p. 141.

The present caregiver remembers about the basic needs of the patient and about the needs which are difficult to express. As we know, the most important things do not have to be verbalized, we can show them. Because this article concentrates on the importance of memory, not on the review of care ethics, we are about to emphasize just one statement: caring is the opposite of forgetting. Both caring and forgetting belong to one person as abilities to care or forget. And if forgetting replaces remembering, caring can also replace forgetfulness, it appears with the presence of the caregiver.

The memory and the map have a lot of common, but the map is merely a fragment of the whole. Personal memory can be considered as a whole; it conjoins on many layers what is inside and outside of the consciousness. If the individual is the origin of shared memory, personal memory is not just a fragment, it is one of the layers of the same, common realm. To forget is to be deprived of the matter, which sometimes is justified by the circumstances of illness. Being forgotten, however, is being excluded from the range of importance. Once taken away, importance disappears with one layer—one person—leaving behind not the whole, but the map with a singular, hollow space. So there is no “whole” anymore, there is only a map, a fragment with a missing piece. In the brain of an AD patient there are many spaces which we can call hollow or damaged. In the early stage patients experience the feeling of loss; with time it becomes blurred and unnamed. The image of the personal and the shared world fades, wanders off irretrievably. Nothing seems to be rational, damaged memory loses the trace of accordance. Sometimes patients also may regain consciousness for a moment. While witnessing the patient’s behavior, we can have at least an idea, the amorphous image of the damage—mostly, lost memory is a chasm. It is an image of forgetting; disease leads to oblivion. In late stages, forgetting becomes easier, leaving most of the memories behind is leaving the memory of loss. Patients often hallucinate; what do they see? Is it a chemical reaction, a coincidence somewhere in the brain, or is it a lost memory?

### III. Reminding. Moral response

“One night Timarchus was taken from the house and led to the river. Two youths washed him with the deference of slaves. Then they led him to some priests, near where the water rose. They told him to drink from two springs. The first they called the water of Forgetfulness. The other was the water of Memory.”<sup>22</sup>

“What day is it?,” “Who are you?”—after such questions, after months of growing hostility or helplessness, AD patients become more passive, until they become unable to communicate. It is the inability to concentrate, to keep eye contact, to use the language properly<sup>23</sup> and finally, to speak at all. Since the person’s memory

<sup>22</sup> R. Calasso, *The Marriage of Cadmus and Harmony*, transl. T. Parks, A.A. Knopf, New York 1993, p. 277.

<sup>23</sup> See, A.R. Damasio, H. Damasio, “Language and the Alzheimer Brain,” [in:] *Connections, Cognition and Alzheimer’s Disease*, B.T. Hyman, C. Duyckaerts, Y. Christen (eds.), Berlin–Heidelberg 1997, pp. 181–189.

lost its ability to remember, caring consists in helping to carry the memory and to remind. Remembering, when it is not evinced, is not enough. The presence of the caregiver rests on being unswayed while facing anxiety and patient's unintelligible memories; in the light of care tides of vexation must leave only what is important and worth the effort—that is, reminding. Comfort is questionable, conditions of caring require everything to complete the minimal needs of the patient, whether they can express their will or not. It is not a requirement to look after every trifling detail. The inconvenience rises up because care is often misunderstood, for example by assuming that duty can be imposed by procedures. Procedures in themselves do not imply care and they cannot impose care. To fulfill the duty does not always mean to care for it. And without care in this specific case, we have only procedures which are only the legal ground, but not the origin of ethics, law or medicine.

There is a difference between two moral acts, that is, *to pass on* and *to preserve*. On the one hand, *to pass on* relates teaching and learning about accepted values. *To preserve*, on the other hand, is associated with the act of acceptance. Values are chosen through individual bearing, but on the basis of shared, common knowledge. Memory, even if shared, will not avoid the personal death and will not guarantee immortality, though it will carry the importance—in and of the individual life. *To solidify* has the sense of caring and avoiding unimportance. One thing may be more severe than death, that is, to die with the conscious of being forgotten. Forgetfulness, when replacing remembering, brings relief, but it remains nameless. It can be noticed only by the witnessing caregiver. Being conscious is the very start of cognition and responsibility; reminding is the personal mindset, the bearing towards others. Carrying the memory is a moral response for the caregiver. The first aim is to remember; to remind the patient, to others and even to oneself, as long as possible, of the very beginning of human presence—care. Because most of what is recognized as personal will be forgotten either way, collective, shared memory is the only possibility to pass on the importance defined and realized by the individual. Thus shared, universal principles of importance may overlook the personal rule of verification, that is, the act of moral acceptance. If we expect any universal principles to be actual and perpetuated, reasons to remain important should be complemented individually. Some universal definitions are necessary, but not sufficient, as long as they do not contain the needful fragment of the individual. Can we find this fragment—moral response—without asking about the memory? Conscious acceptance requires memory and the pattern of responses because moral acts are not a matter of reflex. *Areté* will enable the ease of worthiness, nobility, which come with time and experience, but first cogitation is needed—caring as a cognition of its purpose, not just the object. Dissociation, overtaking the body and the mind, causes empirical collapse and interferes with the reasoning. Without memory there is no cogitation, and thus no conscious decision about relational values either. Without memory we cannot care; for moral response, memories are the background for the moral choice, from recognizing one's own identity, to the consideration and cognition of relational values. Because knowledge and cognition are not assumed as identical, we must add that memories may not represent accurate knowledge, but for example, an inter-

pretation of events. The moment of representation is the reason why memories are firmer than intuitions. What is more important, personal experiencing affects how people become familiar with knowledge—on the one hand, the scientific one, on the other—the knowledge underlying the world of everyday life, often more severe and obligatory than scientific principles, appointed as objective and non-personal. Sooner or later, there comes a moment of verification that helps us to settle. Since patients with neurodegenerative brain diseases may behave differently than in their past, they can act fairly just or completely immoral before they lose capability to make any decision. Concentrating on the moral responses of the caregiver towards the patient is more responsive to the necessity of our times, because of the lack of care that we still observe in the broadly defined world.

“By evocation let us understand the unexpected appearance of a memory. Aristotle reserved for this the term *mnēmē*, reserving *anamnēsis* for what we shall later call search or recall. And he defined *mnēmē* as a *pathos*, as an affection: it happens that we remember this or that, on such and such an occasion; we then experience a memory.”<sup>24</sup> When finding accordance, coherence, mentioned as one of the sylphlike motions of memory, is no longer possible for the patient, then the caregiver is the only external foothold of remembering to gain. If the damaged memory loses the sense of conformity, it immures *being present* and *being missing* at the same time. Only the remembering caregiver can recall the names and meanings, although not for long—for the patient—more likely for others. We see it in sciences, education, art; we seek for it in our families and our own familiarity with the world. There are various ways of reminding and many ways of showing care. Reminding may require the presence of importance, as when people hold hands in the moments of mourning.

Reminders are expressly designed to draw us back from the edge of oblivion by directing us to that which we might otherwise forget. As reminding by its very nature delimits forgetting by constraining and diverting the waters of Lethe, so our consideration of reminding itself may help to delimit the present inquiry and to rescue it from submersion in an ocean of descriptive detail.<sup>25</sup>

Images kept by myths are good examples of holding the importance and passing on human meanings and values. Somewhere in between Mnemosyne and Lethe, we are about to happen, by all means, for a moment. With our own existence we remind not of the passing time, but of the undiminished matter of living and sense of remembering. *To remember*, on the one hand, and *to forget*, on the other, is the natural coalescence with being and leaving, with caring and passing away.

The caregiver is a witness, and deciding which role was first is difficult. We notice when we care, and we care to notice the need of being cared for. Not always, the potential to care responsibly is still on its way to emerge in the global range. “Collective memory has agents and agencies entrusted with preserving and diffusing it. One sort of agent should be of particular concern for those who are interested in the questions of what we should remember and what, if anything,

<sup>24</sup> P. Ricoeur, *Memory, History, Forgetting*, transl. K. Blamey, D. Pellauer, Chicago 2004, p. 26.

<sup>25</sup> E.S. Casey, *Remembering: A Phenomenological Study*, Bloomington 2000, p. 90. The author mentions reminding, reminiscing and recognizing as mnemonic modes.

we should forget—that is, for those who are interested in the ethics of memory. The agent I have in mind is the moral witness,<sup>26</sup> but the author notices that “witnessing only evil or only suffering is not enough.”<sup>27</sup> It means that witnessing is the act of commitment to witness both. But how committed should the witness be to share the experience of suffering with someone hurt? Assuming that evil leads to suffering, we can also assume that experiencing evil emphasizes the matter of *happening*. What happens, has the chance to be recognized and comprehended—to be remembered and reminded. In another text we can read: “For another, although in either case it is individuals who (ultimately) do the witnessing, bearing witness always points beyond itself and cannot be adequately explained or appreciated without reference to its larger social and communal connections.”<sup>28</sup> Witnessing is not just about seeing, it means going beyond connections, to relations. It means *noticing* the state, needs and asking about the presence of self-importance of the other person, here, the patient. Reminding of personal meaning is the essence of the motion of importance. As a result, caring affects both sides—the caregiver and the patient—their moral responses, being active and even passive, reflect “retrospective construction of meaning.”<sup>29</sup> Reminding requires repeating, thus we remind of something that already happened in the past. Everything we have been taught by others is a reminiscence and can occur to be a reminder. In other words, we cannot recognize our home without any memories of it; *home* is not simply a place. It is made of all these settling movements of memory, and because of the relational values it may be either present, or, if affinity and closeness are lacking, it may be missing. Going back to the patient who is already lacking in memories, reminding is one of the last things we can do to them.

#### IV. To Repeat the Movement: On Importance

Repeating already contains the moment of remembering; it sustains also the process itself. Behind the conscious act there is a requirement of the content which is remembered. The pattern of acts that is remembered and reminded appears as the presence and response towards the other—the patient—since it holds the highest meaning of importance.

Acts demand choices, and most of them are moral, thus they have influence on the life of other people and on the environment we live in. Consequently, choices have an influence on responsibility, they lead to values, from utilitarian to the perfect ones.<sup>30</sup> Not time, but memory is the medium for the personal recognition of values. As was suggested before, we seem to remember relational values better than we may explain; we do remember people who made importance present

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<sup>26</sup> A. Margalit, *The Ethics of Memory*, London 2004, p. 147.

<sup>27</sup> *Ibidem*, p. 148.

<sup>28</sup> J. Blustein, *The Moral Demands of Memory*, p. 355.

<sup>29</sup> *Ibidem*, p. 67: „[...] it is this sort of retroactive alteration of the past, constructing a new meaning for it through one’s present choices and actions, that is involved in taking responsibility for one’s past.”

<sup>30</sup> A. Lorzcyk, “O wartości, powinności, obowiązku i odpowiedzialności, czyli o tym, co powinniśmy,” *Ruch Filozoficzny* 67 [4] (2010), p. 704. The author refers to H. Elzenberg.

and made things important enough to be worth the effort of reminding. When we speak of importance, a personal value, we are reaching the question about our future. Without the memory, the question about the future is excluded, because there is no past standing behind the moment we call *now*. And in front of us, there are only missing pieces of the same image, remaining nameless. Firstly, responses *to* and *toward* are the responsibility towards another person. Secondly, there is responsibility in the historical order, and so: for the future, despite our short-sighted purposes; another person should not be treated as means. History does not play its role in reverse, since people think of means and goals. That is why conscience comes to rescue in the recognition of values, but the choice, especially when important, must have its weight. What comes easily, may be equally easily forgotten. Liability allows the ease; repeating enables the reminder to appear and to be recognized. The reminder begins with care.

A moral response is the act toward another person; past acts which were taught are an escalating echo of acts which will be undertaken in the future. But the choice is not made yet, the individual reason to complete the shared world with relational values also includes carrying the memory and caring for the presence of importance. Reminding is the evinced remembering, we remind of the matter of response, reasons, purposes, values and our presence. Why can we choose honesty instead of lying, dignity over unimportance, caring instead of forgetting? It is not only the case of free will. There is no other way than make importance present through care. If happening dissociates the real from the unreal, then what happened is already a fact and individual memories are the layers of this event. Since the individual is the origin of shared memory, personal memory is one of the layers of the same realm. Shared images and notions lead to coherence, compatibility in naming our world—ours. Importance is the repeated ethical motion of the memory, the act of avoiding nullity. When we care, we avoid forgetting. To pass on the thought about importance defined by the individual is the responsibility undertaken by one and all. It emphasizes the importance of one, regardless of the condition, like in the case of AD. The caregiver is the witness and the source; is the embodiment of home, care and presence of importance—regarding both sides in the relation. Besides the act of importance, the motions of the memory are opening, settling, finding accordance, repetitive, they hold the personal pattern of mutuality and sort memories by their meaning. Significance is drawn out or it stays veiled, left to transience, in contradiction to what is happening.

On the question “what is important to you?,” most likely we will mention what we expect from life that is still left, not from death. Yet, if we expect death to bring relief, then life is already lost in the waters of Lethe. What about the relational value?

## Conclusions

Do we have to name ourselves *caregivers* to care? The consideration on the range of moral response is not a reminder about our responsibility, but it reminds us of the relevance of care. By repeating the motions of memory, we repeat gestures, words, acts of care—to pass on the relational values. The motion of impor-

tance, when the memory draws out the meaning and sense, is the most essential. Memory is not merely a biological record of personal memories, it helps to build individual and shared familiarity with other people. Familiarity is settling; to lose memory is to waver. In this article, co-carrying the memory for a patient with memory damage or memory loss was presented as a case study of exemplary moral response. Patients with neurodegenerative brain diseases like AD need to be reminded of their importance in every possible way, since they have lost their sense of familiarity. Still, even damaged memory is one of the layers of the world; we should remember about the presence and absence of values—to remind of what is important in being humane. Relations are the most adequate space for importance and care; they also heal or bring comfort to the patients. Their lives and personal definitions of importance need to be preserved in the moral image of memory, if we expect it to be complete and open for our future.

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