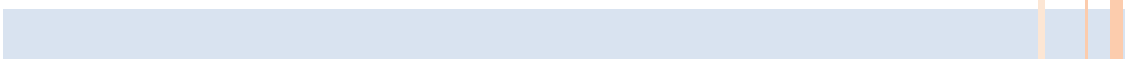
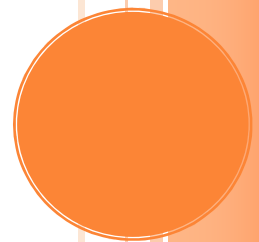


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PHILOSOPHY AND THE UNDERSTANDING OF DEMENTIA

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Introduction

It would be universally agreed that a policy for dealing with the worldwide incidence of the various forms of dementia is more necessary now than ever, and will become increasingly urgent over the next century. A report published in 2012, jointly by the World Health Organization and the charity “Alzheimer’s Disease International”¹, estimated that, in the world as a whole, 35.6 million people were living with dementia in 2010, with 7.7 million new cases being added each year. Caring for those with dementia, already very costly, (US\$604 billion per year), will, the report predicted, become even more so, and the increase in costs will proceed at a faster rate than the increase in prevalence of the disease.

This would amount to a crisis for any disease, but especially so in the case of one like dementia, which is probably equal to cancer in its tendency to strike dread into the hearts of most of us. In some ways, indeed, the terror inspired by the prospect of dementia is even more “existential” than that aroused by cancer. We fear cancer because of the pain, the disability, and the inescapable death sentence which we are afraid it will impose on us. In suffering these consequences, however, we may be a little consoled by the thought that we shall still be here, in our familiar world, where there are people that we know and are known by, with whom we can

¹ *Dementia: a public health priority*, (2012), obtainable from the WHO online bookshop (bookorders@who.int), in English, French and other languages.

share our fears and from whom we can, hopefully, get help and sympathy. By contrast, in the case of dementia, what we dread is that somehow the world in which this suffering will exist will no longer be the one made familiar by such relationships: the self which knew and was known by these significant others will in some sense no longer be here. The “I” that dreads this future will, we fear, not be the one who will experience it, though the bodily “shell” of the present me will still be alive.

The idea of extreme dementia as a kind of “living death”, in which our bodies survive, but we ourselves, in any meaningful sense, have ceased to exist, is very widely held. In the words of a recent leaflet from another charity, Alzheimer’s Research U.K., the onset of dementia is one of our greatest fears because “it challenges our very notions of who we are. If we lose our memories and how we relate to the world, we lose ourselves.”² The peculiar fear that dementia inspires, in other words, is fear of losing one’s self while still remaining biologically alive. The disease is therefore not so much one of brain function, but of the threat which that loss is believed to pose to a feature which we feel to be central to our conception of what it is to be human – that of recognizing and being recognized by other selves. This makes dementia a medical condition unlike most others, and therefore necessarily bears on our thoughts about very practical questions of appropriate treatment and care.

My principal aim in this article will thus be to show, by critically exploring this view of dementia, how philosophy is relevant to practical issues in dementia research and treatment. In our culture, such a claim for the relevance of philosophy to practical questions is liable to be met with suspicion. If we are trying to formulate practical recommendations for care, it is taken for granted that there are two obvious lines of inquiry. First, we need to try to discover what *causes* dementia, and so devise strategies for preventing dementia in the first place, and possibly even for curing the disease, or at least prolonging the meaningful life of sufferers. Discovering causes is above all, surely, a matter for empirical biomedical research –that is, for science, which in the course of the last few centuries has freed itself from philosophical preconceptions. Secondly, we need to understand the progress of the disease, the stages through which it passes from relatively mild beginnings to the end stage, if we are to think concretely about the kinds of care, both medical and social, which are appropriate at each stage. This again, we are inclined to think, is primarily the business of empirical science, including studies of patients in clinical care settings. So the only questions worth asking, in this as in other cases, are *scientific* questions, to be answered by the methods of science. Are we right in this assumption, or is there a case to be made for the position that there is also a role which what we might call *philosophical reflection* could usefully play?

² Fundraising leaflet, Alzheimer’s Research U.K., 2013.

To say that there might be is not to deny the value of the kinds of scientific investigation just mentioned: rather, it is to argue that these investigations themselves presuppose philosophical reflection. To seek the causes of dementia, or to ask what kinds of care might be most appropriate to it, presupposes some conception of *what it essentially is*. It is only possible to determine what causes something if we are clear about what it is that we want to explain. For instance, the “cause” of a journal article’s appearance would depend on what we meant by its “appearance”. Does this mean the author’s act of writing it, or its typography? In the former case, its cause might be another article which had provoked the author to write this one; in the latter, perhaps the cause might be the “house style” adopted by the journal’s publishers or printers. Deciding what we are talking about in this case does not require any deep philosophizing. But it is arguable that determining the “cause” of dementia does. To be clear about the “essence” of such a condition requires us to ask philosophical questions about its *human meaning*. What is it about the condition so defined, with those symptoms and causes, that makes it an “illness”, something that human beings want to have removed or at least alleviated? Questions like this are philosophical, in the sense that we can answer them only by reflecting on the nature of human good and harm.

Determining the human meaning of dementia, or any other disease, is thus not simply a matter of amassing empirical evidence about external symptoms, or internal causes (e.g. the brain lesions which are responsible for the cognitive deficits of people with dementia). Of course, we cannot say what the human meaning of dementia is unless we are clear about the symptoms and causes which define what we mean by dementia; but clarity on the facts of dementia is not enough without reflective analysis and interpretation of the significance of such empirical data, going deeper than these surface phenomena and exploring a vision of a desirable human life from which the symptoms of the condition debar those suffering from it. This kind of reflection is part of *philosophical* methodology, rather than that of *science*, as science is nowadays understood.

Dementia and human well-being

We can usefully begin our philosophical reflections, therefore, with a brief reminder of the facts. We diagnose someone with dementia when that person’s cognitive capacities, especially those involved in memory, progressively deteriorate, with the consequence that the person loses basic abilities required to manage his or her life, to recognize other people (even spouses, children, close friends, and the like), and, eventually, even to know his or her own identity. Any loss of such basic cognitive capacities detracts from well-being: it is one of the penalties of normal aging that it often leads to deficits in memory and loss of control of one’s own bodily functions. But dementia has a different “human meaning” from normal aging. To become old, frail, and forgetful is part of the natural course of a human life – or indeed of the life of any complex animal. We do not think of this decline, therefore, as an “illness”

or “disease”; a deviation from what is “normal”. Any form of dementia, however, *is* thought of in that way. The cognitive deficits involved are not seen as (almost) inevitable parts of the pattern of life, but as unnecessary additions to human suffering. The person him- or herself may well not be aware of these deficits: in fact, a lack of awareness of one’s own cognitive deficits is itself one of those deficits, especially in the final stages of deterioration. As far as the person with dementia is concerned, “suffering” does not necessarily mean “*experienced* suffering” – though those who care for that person are likely to experience profound distress. We suffer from dementia, not in the sense of having inconvenient cognitive deficits, but in the sense that those deficits distort our whole being-in-the-world, our relationship to objects, and especially people, in our world.

Normal aging often brings with it some difficulty in accessing particular facts about one’s own past, or particular bits of general knowledge which one may have acquired in earlier life. An aging person may, for instance, forget meeting someone when she was 20; or forget the Italian word for “suburb”, which she learned in the Italian course she followed when in her forties. More embarrassingly, she may go upstairs to fetch a hairbrush from the bedroom, only to forget what she came up for when she reaches the top of the stairs. Similarly, a male patient with certain kinds of brain injury may be unable to recall the name of the doctor who is coming through the door to see him this morning, as she did yesterday and every day for the past few months – or even that she *is* a doctor. What is striking about these examples is, first, that the apparently inaccessible memories are of *facts*; secondly, that, in the case of the normally aging brain, at least, they may not be *entirely* inaccessible – a prompt from someone else may be enough to bring back the recollection of meeting this person, or of the Italian word for “suburb”, or of the reason for going upstairs. The memory loss in dementia is different in both respects. It is not only factual or experiential memory which is lost, but also the memory of how to do things, and the memory of who other people are, and even of who one is oneself. And these memory losses seem to be *total*: one’s *whole* past seems to be gradually eliminated as dementia progresses.

It is this difference in the apparent scope and nature of memory loss, especially in Alzheimer’s disease, which provides an argument for the practical relevance of philosophy in this case. It gives an existential significance to dementia, in that it is the basis for the widely accepted view expressed in my earlier quotation from the charity leaflet: that dementia “challenges our very notions of who we are”, by which is meant that, if we lose our memories and how we relate to the world, “we lose ourselves”. Total loss of memory, if this is right, means complete loss of selfhood, of that individuality which is an essential part of being a “person” in the full sense – in effect the end of one’s life as a human being, even although one’s biological life as a human organism has not ended.

This is unquestionably a *philosophical* position, since it rests on a definition of personal identity which can be defended only by *a priori* argument, and uses this definition to give a certain interpretation of the empirical facts (it is not simply, in scientific fashion, a conclusion from the empirical evidence). This interpretation, however, carries with it implications, both for the theoretical understanding and for the practical care of people with dementia. It is worth asking, therefore, if another interpretation, with different practical implications, might be possible – or even whether it might be preferable, because based on more coherent philosophical foundations. This is the question I shall ask in the remainder of this article, in part as a way of illustrating the practical relevance of philosophy to the understanding of dementia.

The philosophical position which underlies the claim about a loss of personhood in dementia has a long and distinguished history. It belongs to a central tradition in empiricist thought, of which the most distinguished early representative was John Locke, in a chapter of his *Essay concerning Human Understanding*³. In that chapter (Book II; Chapter XXVII), Locke is discussing the ideas of identity and diversity in general, where, by “identity”, he means that which makes something *the same* thing at different times, and, by “diversity”, that which differentiates it from other things, even other things of the same kind. (Identity and diversity are, in effect, two sides of the same coin). So, the identity of the chair I am sitting on to type this is whatever it is that makes it *this particular chair*, and so the same chair I sat on yesterday, and the day before, and so on.

In thinking about identity in this sense, Locke’s great insight was that criteria of identity must depend on *what kind of thing we are talking about*; or, as he puts it, “to conceive, and to judge of it [identity] aright, we must consider what *Idea* the Word it is applied to stands for ... for such as is the *Idea* belonging to that Name, such must be the *Identity*...”⁴. To use some of Locke’s own examples, a random collection of physical objects, such as a heap of lumps of coal, is only “the same” heap as long as no lumps are removed from it or added to it. But a living organism, such as a plant or animal, can remain the same plant or animal even though the particles of matter of which it is composed are changing all the time, with some being lost and others added. This difference in criteria of identity is because a heap of lumps of coal randomly collected together and a living organism are *different kinds of thing*. What makes, say, a lion the same lion from the days when it is a new born cub to the end of its life is thus not the particular collection of cells which make up its body at any given time (clearly, the cub has a different

³ Various modern editions of this work are available. Probably the best is: John Locke, *An Essay concerning Human Understanding*, edited with an introduction by Peter H. Nidditch, Oxford, Clarendon Press, 1975. In all quotations from Locke, I follow his seventeenth-century conventions of punctuation and spelling, in accordance with Nidditch’s practice.

⁴ Locke, *Essay*, Book II, Chapter XXVII, Section 7.

collection of cells from the old lion), but the continuous life-history which is made possible by this changing set of cells. It is identified as the particular lion it is by having this continuous life-history, from birth to death.

Human beings, considered simply as biological organisms of a particular species, have, in Locke's view, the same kind of identity as other animals. Locke's term for a human being, considered simply as a member of a particular biological species, *homo sapiens*, is "man". So the identity of a man in this sense consists in "nothing but a participation of the same continued Life, by constantly fleeting Particles of Matter, in succession vitally united to the same organized Body"⁵. Considered simply as a "man", a human being is just one type of living organism, parallel with a lion or a parrot. However, - and here we come to the part of Locke's account that is most relevant to our present topic - we must, Locke thinks, differentiate between the identity of a man and that of a "person", because these are two different "ideas". The idea of a "person" is that of a human being as something more than a biological organism: we call human beings "persons", in Locke's view, when we think of them as, not merely animals of a certain shape, but beings capable of intelligent thought. What the word "person" stands for, according to Locke, "is a thinking intelligent Being, that has reason and reflection, and can consider itself as itself, the same thinking thing in different times and places; which it does only by that consciousness, which is inseparable from thinking ..."⁶.

"Consciousness" is the crucial word here. It is "inseparable from thinking", according to Locke, in that, in his view, to think is necessarily to be conscious of thinking: in having an experience, or performing an action, he would claim, I am necessarily conscious that *I* am having that experience or performing that action - in other words, that this is one of *my* experiences or actions, as opposed to yours, or his, or hers. It is this consciousness of certain experiences and actions as being *mine* which, Locke argues, creates my "selfhood", which makes me, the individual I am, distinct from other persons, other selves. It follows, he concludes, that "as far as this consciousness can be extended backwards to any past Action or Thought, so far reaches the Identity of that *Person*..."⁷. My history as a person thus consists for Locke of all those past actions and experiences which I consciously recollect and so which I can acknowledge as mine. Conversely, if I *can't* remember an action or experience, it is not part of that particular past history which constitutes *my* identity as a person. The implication is, surely, that I exist as a person only if, and for as long as, I am conscious of myself as so existing - conscious of being me. A living human being who did not have self-consciousness would be, in Locke's terms, a "man", but not a "person": he or she would have no thoughts, since, for Locke, to

⁵ Locke, *Essay*, Book II, Chapter XXVII, Section 6.

⁶ Locke, *Essay*, Book II, Chapter XXVII, Section 9.

⁷ Locke, *Essay*, Book II, Chapter XXVII, Section 9.

think is necessarily to be conscious that one is thinking. So he or she would be *mindless* – the bodily “shell” of what could be a person, functioning biologically, but without the conscious sense of being a particular individual which is necessary if one is to be *actually* a person in the full sense.

It is easy to see how Locke’s philosophical account of personal identity underpins the fairly widespread popular view expressed in the earlier quotation from an Alzheimer’s Research UK leaflet – that “if we lose our memories, ... we lose ourselves”⁸. It is fairly easy, too, to see why this view should have such a wide appeal. When I ask myself “Who am I?”, it is difficult to see where else I could look than my past experiences, as I remember them. Some, in particular, will strike me as specially significant, as expressing something uniquely identifying about me (these will be the very ones I am most likely to remember). Thus, my first real memory is of experiencing the air-raids on Liverpool as a toddler in 1940. I remember being frightened by the sight of the bombers and the sound of the explosions, and being comforted by the embrace of my mother as she carried me out to the air-raid shelter. This is something which I can now, through memory, identify with as an event in my own past life, and so, for Locke, I, the person who now recalls it, am the same person as the I who originally experienced it, even though I am now radically changed, both in bodily characteristics and in personality. Such memories constitute my sense of my own life as a single narrative, in which the fears of the four-year old and the reminiscences of my aged self are separate but connected episodes, like the earlier and later chapters of a novel or an autobiography. They give me what might be called a “rich” sense of who I am, which is more than what is expressed by the bare statement, “I am me”, and without which there would be no “me” concrete enough to form the basis of personal relationships with others.

All this sounds very natural and plausible. It gains some support from cases like that of someone with total amnesia – someone who even forgets her name, and all other details of her past life. She is still aware of herself as a different self from others – from her doctor and nurses, for instance: so she retains what one might call a “thin” sense of identity. She can still, for example, use the first person singular pronoun, “I” (or its equivalent in other languages). She can still say, “I feel thirsty”, or even more complicated things like, “I feel so frustrated that I can’t remember anything about my past life”. This kind of sense of personal identity must be accepted even by Locke: as we have seen, on his view I can’t feel thirsty or frustrated without being conscious of these feelings as *mine*, and so as having at least a minimal sense of being an individual person. What she can’t do, if she is totally amnesiac, is answer the question, “*Who* are you?”, which would involve linking together various kinds of feelings, thoughts, ambitions, ideals, desires,

⁸ See above, page 2.

wishes, and so on to constitute a whole picture of her personality, or of what is special about *her* life. Others, who know her well enough, perhaps can do this, but she can't. So, if her amnesia is not only total, but irreversible, her sense of having a life of her own, which would provide the background to her present life and relationships, has gone for ever. Even the others spoken of may well feel frustrated when *their* sense of who she is does not meet a corresponding sense of selfhood on her own part.

Some problems with Locke's position

So this account of personhood has a genuine appeal, and it can readily be seen why it has become so widespread in thinking about dementia. There are, however, equally obvious difficulties in it. First of all, Locke implies that my existence as a person extends only so far as my conscious recollections: that is, that it is only what I can remember in this sense that forms part of my life-history as a person (see the passage quoted in footnote 7 above). If I cannot now recall some past experience as my own, then I am not the same person as the one who had that experience. If, as is progressively the case in dementia, I remember less and less, and eventually nothing, of my past experiences, then it follows, according to Locke, that I progressively cease to lose contact with the person that, as we should normally say, "I was". When I can remember nothing, I have no past existence as a person at all. Since a person is essentially a being who exists over time, however, that must mean that at that point I cease to exist as a person at all – that I then "lose myself".

Can this be right? Surely no one remembers *everything* about their past lives: that is a consequence, not only of the loss of memory in dementia, but of the normal circumstances of human life. Very few (perhaps no) human beings remember being born, or the early stages of infancy; most of us remember little even about the later years of childhood – what we tend to have is usually a few flash-backs lighting up the generally unremembered darkness around them. Does it follow, because I can't remember being born, that it wasn't *me* that was born in 1936; or, because I do not remember anything before the age of four, that there was no *me* before that age: or that my patchy memories of later childhood mean that I had only an intermittent existence as a person, until I reached the sunlit uplands of adulthood? Surely not. Further, the adult years of most of us are not *all that* sunlit: we can have fully functioning memories without being able to remember everything about our adult lives. An inability to forget anything is not a sign of a good memory, but of a certain kind of very distressing mental illness. Conversely, an ability to tell a complete story of everything one has done and experienced is not a precondition of having an unbroken life-history: otherwise, since most of us lack that ability, most of us would not have an unbroken life-history.

Perhaps it might be suggested that the difference between normal forgetfulness, in which we can still remember at least *significant* things about our own past, and the condition of someone suffering from end-stage Alzheimer's, is that the latter remembers *nothing* about his or her life. Certainly, total loss of all memories of one's own past seems to be, as is often said, "different in kind, not just in degree" from partial memory loss (of the kind found, for instance, in normal aging). Even if we accept this difference, it would not necessarily follow from it that someone with severe dementia has lost his or her self completely. It might simply confirm that Locke was wrong to base continuing personhood only on the power of recollection.

Another kind of objection to Locke which is relevant is the argument put forward by one of the most acute of Locke's early critics, Bishop Joseph Butler⁹. Butler argues that Locke's position, that consciousness *constitutes* personal identity, is circular. "One should really think it self-evident," he says, "that consciousness of personal identity presupposes, and therefore cannot constitute, personal identity, any more than knowledge, in any other case, can constitute truth, which it presupposes"¹⁰. The point is simple: we can't be conscious of something unless there is such a thing already in existence to be conscious of: so it can't be consciousness of the thing which brings it into existence. It can't be my consciousness of Paris that makes that city exist, because I couldn't be conscious of Paris *unless* it already existed. Similarly, I can only be conscious of being me if there already exists a "me" to be conscious of (and, Butler might have added, to be capable of conscious awareness of anything).

If we accept Butler's argument, then the only role which consciousness can play in relation to personal identity is for it to be the means by which we become aware of who we are. Then, as suggested above, we could distinguish between having a "thin" sense of my own identity (a sense of being "me", rather than "you", but not of *who* I am), and a "rich" sense of my own identity (the ability to give a more detailed account of who I am). We could then say that loss of all memories, as in the most severe phase of Alzheimer's, is truly a loss of all the richness of a person's sense of her own individuality: hence the tragedy of the disease for those who love that individual, and indeed for the individual him- or herself. It does not follow, however, that a person, even one with severe Alzheimer's, loses *all* of his or her identity as a person, still less that he or she ceases to be a "person" at all, and is reduced to a mere living organism. All that is necessary for being a person is what I have called the "thin" version of self-consciousness. One can surely have experiences of various kinds - simple sensations of pain and pleasure, for example,

⁹ In his essay, "Of Personal Identity", reprinted in Perry, John (ed.), 1975, *Personal Identity*, Berkeley, California, University of California Press, pp. 99-105.

¹⁰ P.100 in the Perry reprint.

and be conscious of having them, without having the ability, through memory, to connect them to past experiences. The inability to connect them in this way certainly precludes a rich and complex understanding of one's present experiences, but that kind of understanding cannot be a prerequisite of being a "person" in a morally relevant sense.

A more fundamental objection to Locke's account, which reinforces this point, is that it focuses too much on an "over-intellectualised" conception of memory – namely, on memory as the *conscious recollection* of events and experiences in one's past. It is not only my memory of living through the Blitz (for example) which makes me the person I am, but the particular habits of behaviour or style of doing things which are peculiar to me – gestures, mannerisms, ways of talking, facial expressions, and the like. These are features of my identity of which I am generally not conscious (and, to the extent that I become conscious of them, they are likely to seem less "authentic", more a matter of play-acting). They are not, therefore, part of that sense of my own identity which I arrive at by reflection on my past experiences. Indeed, they are more deeply rooted than that: it seems plausible to attribute them to such causes as my genes, or my experiences in early infancy, before I became, or could become, conscious of myself as an individual. For *others*, nevertheless, they may more clearly identify me than those characteristics which I consciously attribute to my "self". Being independent of memory and self-consciousness, however, makes them more likely to survive loss of such self-consciousness.

This brings out an important feature of personal identity, neglected by many philosophers. My identity is defined at least as much in "third-person", as in "first-person" terms. That is, a satisfactory answer to the question, "Who am I?" is more likely to be given by others, on the basis of their observation of me, than by myself, on the basis of my own reflections on my life. Because of this, even if a person with dementia does not recognize her loved ones, as long as *they* recognize *her*, she remains a person, and that individual person. Instead of describing people with end-stage Alzheimer's as "the living dead", it would be better – more accurate and more ethically sensitive – to say that they were people who had lost all that gave them a rich personality in the eyes of others, but nevertheless retained the minimal core of their personhood.

Conclusions

To see why all this matters is to see why philosophy is relevant to thinking about dementia. The view of dementia as a "loss of self", or as a kind of "living death", is, as was said earlier, a very common one, and in many ways very natural. To watch the seemingly inexorable progression of dementia, especially Alzheimer's, is to observe the decline of all that seems to be most individual, and therefore most

human, about a person. It is particularly distressing for those who are emotionally closest to the person, as they see the progressive loss of all that they shared with that person, which they still preserve, and which he or she formerly preserved, in their common stock of memories.

While this conception of the meaning of dementia is a natural outcome of our encounter with cases of the condition, however, it is essentially a *philosophical* conception, not a *scientific* one, so it is not testable solely against the empirical evidence. The same empirical evidence (our observations, just referred to, of actual cases) can be interpreted differently, in light of different philosophical analyses of the concepts of self and memory and the relation between them. The objections I have brought in this article against the Lockean conception of persons, in its bearing on the way we think about people with dementia are also arguments for a different conception. The central difference is that the Lockean view is over-intellectualised, Cartesian, identifying our humanity and individuality too closely with explicit self-consciousness, “reason”, and memory as a “cognitive capacity”. The alternative view, implicit in my objections, is of a self as a human animal. It is animal, in that the individuality of each self is manifested as much in behaviour and other characteristics observable to others as in the person’s internal self-conception, embodied in the autobiographical account which she may give of herself. It is human in that this self-conceived autobiography is vitally important to what I have called the “richness” of each individual human being, giving complexity and a particular colouring even to the mannerisms, gestures and quirks of behaviour just spoken of.

The Lockean/Cartesian conception of the self creates uncertainty about the humanity and individuality of at any rate severely dementing people, and thus equal uncertainty about how they should be treated, both ethically and clinically. Ethically, it suggests the dangerous view that a human being with end-stage dementia is no longer a “person”, in that morally relevant sense in which persons are beings deserving of moral respect: he or she has become, as it is often, worryingly, expressed, a “mere vegetable”. Clinically, it is relevant in that it suggests the aim of treatment in earlier stages of dementia should be to find ways of preserving the “rich” sense of one’s own individuality for as long as possible. (I shall explore this suggestion in more detail in a later article). In ways like these, philosophical reflection can have a practical bearing on the ways we deal with people with dementia, as friends and relatives or as professional carers.