

Dementia mind, meaning, and the person

Julian C. Hughes
Stephen J. Louw
Steven R. Sabat
Editors

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Dementia

mind, meaning and the person

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Dementia

mind, meaning, and the person

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For
Anne, Olli, Emma, Luke,
Stephanie and Anita,
And in memory of Gio, Irene, Jack, Rod, Sophia, Sam,
Terry, and Bob Grossman

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Preface

Dementia is not the hottest topic in the philosophy of psychiatry. The excuses for this are several. In some countries, after all, it is dealt with by physicians (geriatricians or neurologists), not by psychiatrists. This is probably because it is readily thought of as a brain disease and not as a mental illness. In addition, the symptoms of a condition such as schizophrenia seem more likely to raise issues of interest to philosophers: thought insertion, delusions, hallucinations and the like. But the tendency to overlook the philosophical issues raised by dementia is a mistake.

For one thing, as the practitioners in this volume make plain, it is not *just* a brain disease. It affects the whole person. For this reason, as the philosophical discussions in this volume show, it is a condition that raises in a dramatic form issues about personhood. It should not be forgotten that people with dementia can also be troubled by hallucinations and sometimes by delusions, or at least confabulations. People with dementia can also become depressed, aggressive, apathetic, and seem to change personality and lose insight. Not everyone with dementia suffers in the same way and not all to the same degree. But it should be clear there is more than enough grist for the philosopher's mill. And our belief, in putting together this volume, is that philosophical contributions are valuable, because they can help to sharpen our thoughts about what we do as practitioners working in a variety of ways to help people with dementia.

For example, do people with dementia lose their minds? Do they lose their selfhood? What are the criteria employed in answering these questions and what supporting evidence is provided? Would our belief that such people have lost their minds and selfhood affect the ways in which we treat them? Does our treatment of them affect people with dementia and if so, how? If our behaviour does affect them in particular ways, what would that mean for them? Furthermore, as dementia becomes more common, society at large needs to think clearly about how it views and treats people with dementia.

The book stemmed from a conference with the same name that was held in Newcastle upon Tyne in late 2002. This is not simply a collection of the papers presented at that conference: not all of those involved with the conference appear in the book and not all of the authors attended the conference. The spirit of the conference, however, is maintained. The stated aim of the conference, which was a joint meeting of the Philosophy Special Interest Group and the Faculty for the Psychiatry of Old Age of the Royal College of Psychiatrists, was "to foster discussion of the philosophical issues and conceptual difficulties raised by dementia". The preamble continued: "The philosophical discussion will be informed by the realities of dementia and, we hope, will itself affect the way in which dementia and people with dementia are regarded. The interdisciplinary

nature . . . is intended to encourage a broad understanding of dementia". These are the aspirations of the present volume too.

In drawing together such a volume we have faced an unavoidable difficulty. We hope it will be read by people from various disciplines and none. Inevitably, then, some people will know more about dementia, but will be unfamiliar with philosophical writings; others will be interested in philosophy, but know little about dementia. There may be the occasional "lay" reader who knows relatively little about either subject. There are two things to say. First, the authors have tried to write in a way that is as accessible as possible, whilst not detracting from the depth of their thoughts. Some chapters will be more challenging than others for particular readers, but—given our own different backgrounds as editors—we believe that the book will be read with profit by people with and without schooling in various disciplines. We hope so!

Secondly, we have written our own introductory chapter with the intention of sketching the field. We describe, albeit briefly, some basic features of dementia; we point towards sources of further information; we paint some of the philosophical and clinical background and set the chapters in context. You will have to judge to what extent we have been successful. The chapters that then follow move from philosophical to more practice-based discussions. Many of the chapters, however, contain insights from both philosophical reflection and from practical experience.

There are a number of people to whom we owe thanks. We have received ever patient and friendly help from the staff at Oxford University Press to whom we extend our sincere thanks: Richard Marley and (more recently) Martin Baum have acted as encouraging commissioning editors since the idea for the book arose; Carol Maxwell has been our main point of contact throughout the writing process and has dealt compassionately with our concerns and blunders; Diana Gallanaugh has provided meticulous and thoughtful copy-editing; whilst Helen Hill has directed the proceedings with great efficiency and care during the production phase. We must also thank our authors, who have put up with varying amounts of badgering, but who have remained remarkably friendly none the less. We shall remain extremely grateful to them for their considerable contributions. We should also thank the people with dementia, whose presence, generosity of spirit, honesty, and trust have informed and inspired many of the authors of the chapters that follow.

On a more personal note, we must thank Bill Fulford for encouraging us to work on this book in the first place. Little occurs in the world of philosophy of psychiatry without Bill's involvement. It has been a great support to have his enthusiastic backing throughout. Agnes Muse has provided a good deal of over and above secretarial help with the book. Joan Louw, Anne and Luke Hughes have provided last minute assistance with proof reading. We are enormously grateful to all those who have helped.

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1 Seeing whole

Julian C. Hughes, Stephen J. Louw,
and Steven R. Sabat

Introduction

Whole sight; or all the rest is desolation. (Fowles 1978, p. 7)

There is a sense in which the story around dementia appears to raise no particular problems. We grow old and we decline. Part of this decline is mental. We become forgetful, which may be more or less of a problem. If the decline is too marked, or if it is too marked in a certain way, we shall need care and perhaps protection, perhaps from ourselves. If we suffer, we can be treated and the suffering comes to an end with death.

The sense in which the dementia story raises no particular problems is probably worth seeing. Dementia is an inevitable part of life now that we are an ageing society. We cannot avoid this fact about the world. Dementia signifies a deterioration in the person's brain and, hence, a loss of mental functioning. In a sense, then, dementia is like other physical illnesses; it causes specific disabilities that have characteristic consequences: failures in the person's ability to do certain things. These need to be compensated for by those around. The story about dementia is just the story of a chronic age-related disease, which in the end is terminal.

It would seem a travesty, however, to leave things like this. For a start, already there has crept into the account the idea that what makes dementia a disease is something to do with failure of action or 'ordinary doing', which is (intentionally) redolent of Fulford's work (Fulford 1989) on the nature of mental illness; and which should, therefore, alert us to the possibility that, *at the heart of the diagnosis of dementia lurks some sort of evaluative judgement*. And this should be something of a surprise; for dementia (out of all the 'mental' illnesses) is the most objective, most like a physical illness with definite pathology, objective tests, and rational treatments. Thus, just to take the three most common forms of dementia, *Alzheimer's disease* is typically a gradual, but progressive, loss of cognitive function, with 'forgetfulness' occurring early, but with the emergence of other deficits over the course of years, all of

which can be correlated with the findings of particular pathological lesions in the brain (plaques and tangles); *vascular dementia* has a more sudden onset, where the problems in the person's mental powers reflect underlying damage relating to the blood vessels in the brain, either blockages or bleeds—that is, strokes or mini-strokes; and *dementia with Lewy bodies*, characterized more recently, usually presents with fluctuating cognitive deficits (which may be more to do initially with visuo-spatial skills than recall), well-formed visual hallucinations (often involving small animals or people), and the emergence of parkinsonism (for example, a blank expression and slowness of movements, tremor being milder and less common than in classical Parkinson's disease), with Lewy bodies (the lesions usually confined to structures towards the base of the brain and associated with Parkinson's disease) throughout the cortex.¹

This all sounds rather definite, so in what sense is 'dementia' an evaluative notion? Well, although established criteria stipulate that a definite diagnosis can only be made post-mortem, so that the diagnosis of any of these conditions in life is only 'probable', there turn out to be no clear boundaries at the neuropathological level. Consider this, for instance, from experts in the field in one of the most influential textbooks on the subject:

The pathology of [Alzheimer's disease] defies precise definition at present. This is because its individual components all occur to some extent in normal ageing. (Esiri and Nagy 2002, p. 107)

This is not to say, of course, that a definite diagnosis cannot be made. Clinically and pathologically some people have very clear-cut Alzheimer's disease. However, many have concomitant vascular pathology; and cortical Lewy bodies can be found in Alzheimer's disease too. Recognizing this lack of determinacy may be useful scientifically, because it may lead to a greater concentration on the ageing brain *as such*, rather than encouraging a focus on particular disease entities, which may or may not be natural kinds (of which more later). But what it certainly does is this: it lets the evaluative cat out of the factual bag. At the most objective end of 'mental' illness (that is, in the field of 'organic' dementias) it turns out there is no hard scientific boundary between disease and normality.² Lines can be drawn, but their exact location is a matter of evaluative judgement based on correlations between neuropathology and symptoms and signs. But which symptoms and signs? How much forgetfulness is pathological? What counts as normal ageing?

Of course, there is nothing new in this as far as mental illness is concerned. As Dickenson and Fulford (2000) point out, historically there has been a tug of war regarding the notion of mental disorder between those favouring a medical model and those favouring a moral model. Albeit there are important criticisms to be made of the tendency to favour the medical model—and a number of the authors in this book have made such criticisms extremely cogently here and elsewhere (cf. Chapter 15 by Downs and colleagues)—if things move too far in the direction of the moral model (leading to a refusal

to acknowledge that any mental illness is caused by disease), bad consequences might ensue:

Push the balance too far towards an exclusively medical model, and psychiatry slides from a properly medical role into coercive functions; . . . But push the balance too far towards an exclusively moral model . . . and we end up denying the resources of medicine to those who most desperately need them. (Dickenson and Fulford 2000, p. 55)

Similar dangers lurk in our judgements about what will and will not count as normal ageing and normal forgetfulness.

For the *cognoscente*, this will bring to mind concerns about the ‘diagnosis’ of mild cognitive impairment (MCI), which is thought of as a pre-dementia state—one in which not everyone will go on to develop the disease, but one for which drug treatment might one day be routinely recommended. This is the territory covered by Bavidge (Chapter 2) in his elegant discussion of the notion of ‘the shape of our lives’ and how this relates to the idea of human nature, which is an inescapable amalgam of facts and values and which in the end is inescapably shaped by our mortality.

In the face of diagnostic indeterminacy, it is worth bringing to bear philosophical thoughts about ‘natural kinds’, to which we have already alluded. Inasmuch as we can think of the dementias as disease entities, they could be accorded the description of natural kinds. These are ‘a kind of event found in nature and hooked up to other events by laws of nature’ (Hacking 1995, p. 59). Natural kinds are events in nature, but this means things or objects like books, animals, or instruments, or characteristics such as the colour gold. There is a sense in which the dementias are like this. They are (in a sense) disease entities: we can say without much doubt that so-and-so has dementia and that probably (by which we shall often mean that the chances are at least 90%) it is Alzheimer’s disease. In addition, having this diagnosis will have causal consequences, in that certain types of deterioration can be predicted and certain forms of treatment will tend to help.

Yet our discussion of the neuropathology of the dementias, and the notion of MCI, and the indeterminacy with respect to normal ageing, all point to the conclusion that not every case of ‘forgetfulness’ or ‘cognitive impairment’ can be regarded as an example of a natural kind. These are neither always clear-cut entities in nature, nor in the clinic. Still, we may wish to say that they are kinds of some sort. Hacking usefully provides the notion of *interactive* kinds. Whereas natural kinds are *indifferent*—that is, to be a goldfish is simply *that* and you do not become more or less gold (or more or less fishy) by having been described in this way—an interactive kind is one that is affected by the description that it is given. Interactive kinds are such

that, when known, by people or those around them, and put to work in institutions, change the ways in which individuals experience themselves—and may even lead people to evolve their feelings and behaviour in part because they are so classified. (Hacking 1999, p. 104)