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Julian C Hughes: The practical relevance of philosophy in dementia care

The practical relevance of philosophy in dementia care

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Introduction: two-way traffic

One of the inspiring things for me when I entered psychiatric practice, having previously studied philosophy, was the thought that there is, or should be, two-way traffic between philosophy and psychiatry¹ (Fulford 1991). I shall go on to argue that one of the ways in which philosophy is practically relevant to dementia care is that it can help with ethical thinking. At first blush, it is very easy to imagine the moral philosopher coming along to practitioners in dementia care and helping them to solve some of their practical difficulties. It is helpful to consider the ways in which we might do this.

The inspiring thing for me, however, was the thought that the traffic goes in the other direction too: clinicians have something to teach philosophers. There are experiences understood in clinical practice that need to be grasped by philosophers, which might be helpful in shaping thought and reasoning. The traffic in this direction ranges from large-scale conceptual concerns in the philosophy of psychiatry, for example about how thought insertion affects our view of consciousness² (Bayne 2013), to nuanced issues about the relevance of certain facial grimaces in terms of our understanding of a particular person with dementia and,

¹ K.W.M. Fulford, "The Potential of Medicine as a Resource for Philosophy", *Theoretical Medicine*, 12 (1991) 81-85.

² T. Bayne, "The Disunity of Consciousness in psychiatric Disorders", in: K.W.M. Fulford, M. Davies, R.G.T. Gipps, G. Graham, J.Z. Sadler, G. Stanghellini, & T. Thornton (eds.), *Oxford Handbook of Philosophy and Psychiatry*, Oxford: Oxford University Press, 2013, p.673-688.

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therefore, our appreciation of the role of grimaces (or embodiment) in our understanding of personhood generally³ (Hughes 2013a).

One of the reasons I think this second direction of travel has been inspiring for me is that, although on the one hand I believe it to be true, on the other hand, I find myself wondering in what sense it *really is* true. Clinical practice and philosophy inspire me to ponder this uncertainty. It is towards explication of this uncertainty that I think I shall be moving in this paper, so let me say a little more about it in anticipation. Of course, as a practitioner, I can say to the philosopher: You see that grimace, which might have been a smile, we take it that this is a sign that he no longer wishes to eat'. It is a sign, therefore, of agency, even in circumstances when rationality is not obvious, when language is absent, when we have no reason to believe that there is any significant cognitive function of the sort that might be taken to underpin personhood, in one sense of that word. But there still seems to be bodily autonomy or agency (Dekkers 2010)⁴. My uncertainty here is not about all of this being true. It is simply that I guess most philosophers would grasp this pretty quickly. If there is this sort of traffic going from practice to philosophy, it does not seem to be very laden down. It is light traffic.

Still, I want to say, there *is* something else about practice that should speak to philosophy, which we *know*, but which can be hard to enunciate. It seems to me it is about the spaces that we create in therapeutic work, the meanings which are co-created between human beings. There may be various ways to put this, various avenues down which we might travel, from a discussion of tacit knowledge ⁵ (Thornton 2013) to talk of the similarities between aesthetic and clinical judgments (Hughes 2014) ⁶. Important things happen in these spaces – everything from practical and clinical to ethical and metaphysical – and these realities, known by practitioners, might constitute weightier traffic for the philosophers to consider.

But, since I am meant to be considering the practical relevance of philosophy to dementia care (rather than the other way around), is this to the point? Part of what I want to conclude is that philosophy can heighten our awareness of, or prime us to, the *significance* of what we are doing. The inspiring thing about the two-way traffic, perhaps, is that it flows in both directions *simultaneously*. Philosophical reflection, simply put, makes me more reflective as a practitioner and, as such, I

³ J.C. Hughes, "'Y' Feel Me?' How do we Understand the Person with Dementia?", *Dementia*, (2013), 12/3 (2013) 348–358.

⁴ W. Dekkers, "Persons with Severe Dementia ad the Notion of Bodily Autonomy", in: J.C. Hughes, M. Lloyd-Williams, and G.A. Sachs (eds.), *Supportive Care for the Person with Dementia*, Oxford, Oxford University Press, 2010, p.253-261.

⁵ T. Thornton, "Clinical Judgment, Tacit Knowledge, and Recognition in Psychiatric Diagnosis", in: K.W.M. Fulford, M. Davies, R.G.T. Gipps, G. Graham, J.Z. Sadler, G. Stanghellini, & T. Thornton (eds.), Oxford Handbook of Philosophy and Psychiatry, Oxford, Oxford University Press, 2013, p.1047-1062. ⁶ J.C. Hughes, "Editorial: The aesthetic approach to people with dementia". *International Psychogeriatrics*. (2014).

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am likely to be prone to understanding meanings, or significances, which are of philosophical importance. None of this is guaranteed, of course, but it is possible.

I shall move on to discuss ethics and, in particular, the notion of personhood. This will lead me to consider the importance of the human person perspective. Then I shall set out an argument, albeit in a summary fashion, about normativity as an example of a more philosophical topic in order to show its relevance to practice, which will culminate in the idea of dementia-in-the-world.

Just ethics?

So, it seems clear that the philosopher, especially the moral philosopher, can help those who are engaged in dementia care. Take the issue of artificial feeding for people with severe dementia. It is common that people with severe dementia start to lose control of their ability to swallow safely; and some of them also just seem to stop wanting to eat or drink. One response to this is to consider some form of artificial feeding, perhaps a naso-gastric tube (NGT) or a percutaneaous endoscopic gastrostomy (PEG) tube; the first goes via the nose into the stomach, the second goes directly through the abdominal wall. In a person with severe dementia, should these types of artificial feeding be used? Ethicists or moral philosophers can point to the doctrine of ordinary and extraordinary means as a way to decide. This doctrine suggests that there is a moral obligation to provide ordinary but not to provide extraordinary treatments (or investigations). One way to understand this is to consider "extraordinary" those treatments which are both unlikely to be effective (i.e. they are likely to be futile) and which are also burdensome to the person and to the family. Empirical evidence suggests that artificial feeding is not efficacious (Sampson et al., 2009) and it is likely to be burdensome, therefore we are not morally obliged to provide artificial nutrition. We might do so under particular circumstances, but we are not morally obliged to do so under normal circumstances. Instructing those involved in dementia care about this doctrine can be useful and is a way in which philosophy might be relevant to dementia care. It is helpful purely in terms of setting out clearly a coherent way in which to think through such issues. The doctrine would also be relevant to the use of cardiopulmonary resuscitation in severe dementia or to the use of intravenous, as opposed to oral, antibiotics in the same circumstances.

The doctrine of ordinary and extraordinary means is not, of course, a panacea for such moral problems. Clinicians still have to be sure that they have appropriate empirical data upon which to decide that the treatment is likely to be futile for this individual. They still have to make a further evaluative judgment about the extent to which the treatment might be burdensome. And, even if they

⁷ E.L. Sampson, B. Candy & L. Jones, "Enteral Tube Feeding for Older People with Advanced Dementia", *Cochrane Database of Systematic Reviews*, 2 (2009). Art. No.: CD007209. doi: 10.1002/14651858.CD007209.pub2.

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are sure the treatment would be regarded as "extraordinary", they still have to decide whether or not they will give it, because the doctrine does not say they must not give it, only that it is not morally obligatory to do so. Furthermore, not everyone accepts the doctrine and there are arguments about its standing8 (John 2007).

Well, but at this point some doubts might start to creep in: how useful are these extra layers of thought to the practitioner? Practitioners are, after all, looking for practical solutions. They do not have the time or inclination, it might be said, to embark on a process of complicated quasi-conceptual reasoning.

I still think that clarification is one way in which philosophy is relevant to dementia care. In a recent systematic qualitative review, Strech *et al.*⁹ (2013) identified a spectrum of 56 ethical issues in clinical dementia care. Clarity of thought will be important in dealing with each of these issues, whether this involves using a well-established doctrine or whether it involves figuring out an approach which accords with our moral principles and intuitions.

For example, in the UK the Nuffield Council on Bioethics produced a report entitled Dementia: Ethical Issues¹⁰ (Nuffield Council 2009). This starts by setting out a six-part ethical framework intended to help those who face day-to-day dilemmas in the care of people with dementia. The framework is a means to help practitioners to order their approach to any given problem. It is based on established ethical principles, but also on philosophical ideas which reflect sociocultural norms and expectations. The framework is philosophical in that it is to do with concepts and seeks to reflect underpinning ideas and values rather than empirical facts. The first component, nevertheless, starts by stressing the importance of facts. It is a case-based approach to ethical decisions in which, having identified the particular facts relevant to the case, they require interpretation in the light of the relevant values and the case needs to be compared to other similar cases to look for ethically relevant similarities and differences. The second component stresses that the nature of dementia is that it is a brain disorder, which is harmful to the individual. The third suggests that, none the less, with good care and support, people with dementia should be able to live their lives well, with a good quality of life. The fourth component stresses the person's autonomy and wellbeing. The emphasis is on autonomy in the context of relationships, i.e. it is relational autonomy that counts. Autonomy is promoted through our relationships. Well-being is to be thought of in terms of the person's moment-to-moment well-

 ⁸ S.D. John, "Ordinary and Extraordinary Means", in: R. E. Ashcroft, A. Dawson, H. Draper and J. R. McMillan (eds.), *Principles of Health Care Ethics* (2nd), Chichester, John Wiley & Sons, 2007, p.269-272.
⁹ D. Strech, M. Mertz, H. Knüppel, G. Neitzke & M. Schmidhuber, "The Full Spectrum of Ethical Issues in Dementia Care: Systematic Qualitative Review", *British Journal of Psychiatry*, 202 (2013) 400–406.
¹⁰ Nuffield Council (2009). *Dementia: Ethical Issues*. London: Nuffield Council on Bioethics. Available at http://www.nuffieldbioethics.org/dementia [last accessed 24th May 2014].

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being, as well as in terms of longer-term factors such as mental ability. Autonomy and well-being are both to be understood in connection with the interests of family and other close carers. The fifth component emphasizes the importance of acting in accordance with the ideals of solidarity: that is, seeing that we are all inter-dependent and that people with dementia are fellow citizens. Finally, the last component is about recognizing personhood, identity and value, which are held to persist even into severe dementia.

If we take just one possible area where there can be dilemmas in care, to do with the use of assistive technology to help care for people with dementia (e.g. the use of electronic tags or tracking systems to find people who might get lost if out walking alone), the report sets out factors which will need to be considered. These include: the person's own views and concerns, for example about privacy; the actual benefits likely to be achieved; the extent to which carers' interests might be affected; and the concern that loss of human contact might result from the use of certain technologies (Nuffield Council 2009, paragraph 6.12) ¹¹. Both in its overall framework, then, and in connection with particular issues, we see philosophical work being done which is relevant to dementia care. Ways of thinking, issues and concepts are being set out for the practitioner to consider and these are, in turn, based on values, intuitions, principles and moral theories.

This might, therefore, seem to put to bed my creeping doubts about the extent to which these ethical reflections could be seen as just more words to be added to the complexity of clinical, practical decision-making in dementia care. Indeed, both clarification of arguments and setting out coherently ways to proceed are things that philosophers can do usefully. But because ethicists do not seem able always to agree and because, even when there is an agreed framework, further evaluative decisions are required, it might still be questioned whether ethics is of much relevance to practitioners once we get beyond guidelines or simple doctrines that can easily be put into effect. If it is just ethics (in the sense of some sort of contribution to codes of practice) that might seem fair enough. Practitioners can put up with the so-called four principles of medical ethics: we should do good and avoid harm; we should respect the wishes of the patient and consider resources 12 (Beauchamp and Childress 2001). Ethics presented thus can give us a framework for our thinking and can help to determine what we do, as long as there are no awkward conflicts between the principles. But isn't it actually the case that ethical issues seem to raise broader issues so that it is never just ethics? We are always

¹¹ Nuffield Council (2009). *Dementia: Ethical Issues*. London: Nuffield Council on Bioethics. Paragraph 6.12. Available at http://www.nuffieldbioethics.org/dementia [last accessed 24th May 2014].

¹² T.L Beauchamp & J.F. Childress, *Principles of Biomedical Ethics*, 5th edition, Oxford, Oxford University Press, 2001.

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straying into more philosophical territory. To what extent is this straying relevant to practitioners?

Personhood

We have already seen evidence of this straying into philosophical fields in *Dementia: Ethical Issues* (Nuffield Council 2009) ¹³. The ethical framework presented in that report was not some simple guideline, but instead it touched upon some complex and profound concepts such as solidarity; and it also talked of personhood, to which I now turn. I want to consider it specifically in relation to ethics and dementia care.

Of course, personhood raises all sorts of metaphysical questions, for instance about the nature of personal identity (Hughes *et al.* 2006)¹⁴. But our understanding of personhood can also be regarded as the foundation of ethics. In human society, what is right and wrong is right and wrong in connection with human persons. Even if the right or wrong is done to something non-human, an animal say or to the environment, it is right or wrong because it is the action of a human person as such. If a tiger kills the pig of a peasant, it has not done anything morally wrong. In fact, this is (in a sense) what tigers should do. The actions of persons, however, even if performed alone without involving any other persons, are still actions which can be described as good or bad, right or wrong. This is a normative claim, but it is one I wish to regard as foundational. Human actions are significant, not solely because of any actual or potential effects, but also because they influence what we become. Moreover, they *have significance* in the context of the human world.

It is the notion of personhood that picks out the moral and legal significance of our standing as human beings in the world. To deny me personhood means to undermine my status as a bearer of those rights which are constitutively human. There has been a trend to regard personhood in terms of a narrow account based on cognitive function, which is then a threat (because of declining cognitive function) to the standing of people with dementia as persons (Hughes 2001)¹⁵. But a broader account can be given which characterizes the person as a situated embodied agent (Hughes 2011)¹⁶. The agentive nature of human persons, coupled with the fact that all clinical decisions are at one and the same time ethical decisions (Hughes 2013b)¹⁷, means that those working in clinical practice are prone to be faced by

¹³ Nuffield Council (2009). *Dementia: Ethical Issues*. London: Nuffield Council on Bioethics. Paragraph 6.12. Available at http://www.nuffieldbioethics.org/dementia [last accessed 24th May 2014

¹⁴ J.C. Hughes, S.J. Louw & S.R. Sabat, S. R. (eds.), *Dementia: Mind, Meaning, and the Person*. Oxford, Oxford University Press, 2006.

¹⁵ J.C. Hughes, "Views of the Person with Dementia", Journal of Medical Ethics, 27/2 (2001) 86-91.

¹⁶ J.C. Hughes, *Thinking Through Dementia*, Oxford, Oxford University Press, 2011.

¹⁷ J.C. Hughes, "Ethics and Old Age Psychiatry". in: eds. T. Dening & A. Thomas (eds.), *Oxford Textbook of Old Age Psychiatry* (2nd edition), Oxford, Oxford University Press, 2013, p.725-743.

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ethical dilemmas in their decision-making. But the situatedness of persons means, moreover, that our actions as agents must inevitably have significance, precisely because they are the actions of human beings in the world (even if I am the sole human being in my world). Personhood is fundamental to ethics because our sense of right and wrong and good or bad comes from our being in the world as beings of this type with these instinctive and natural concerns, which *constitute* our being as beings of this type.

Ethics, then, is not just ethics, because it points towards a view of the world which is inevitably imbued with normative concerns on account of the viewpoint, which is the human person perspective (Hughes 2011, pp. 223-250)¹⁸. The human person perspective is one which is inherently ethical, which is imbued with meaning and which is uncircumscribable, because the possibilities for human beings cannot be shut down: there is always another facet of human life to be explored or discovered. But the key things I wish to highlight here are both that ethics is characteristic of human persons as such and that ethics springs forth from persons as such. To understand our ethical concerns, therefore, is to understand what it is to be a person. The human person perspective just is an ethical perspective with normative entailments and commitments. And a corollary is that ethics is never just ethics, because to do the right thing, to act in a good way, means to be rightminded as a person, it entails being a good person. To be moral is to be a good sort of person. We might say that it is to flourish as a person, which takes us into the territory of virtue theory. But I think this is right, because to pursue moral actions and to make ethical decisions is not just to be able to apply a framework or follow principles or guidelines, it is to be a certain sort of person. It requires the dispositions and type of character defined by the virtues, which are the dispositions and character that allow persons to flourish or to do well humanly.

Ethics is practically relevant to dementia care for obvious reasons. Moral philosophy is helpful inasmuch as it contributes to clarity of thought and argument. But beyond the principles, rules and doctrines of ethics is the inevitability of the human person perspective. Ethical obligations flow from our nature as persons as such. Hence, our thoughts about personhood are also relevant to dementia care, because a whole set of assumptions follow. If, for instance, we do not regard people with dementia as persons, we may not feel the need to treat them in particular ways. More than this, however, it should be clear that, on my view, the relevance of ethics to dementia care is that it inevitably involves consideration by one human being of the needs and standing of another human being as a person. It highlights the relevance to ethical thinking of that person-to-person encounter, which is the bedrock of clinical work. Nowhere, I am inclined to say, is the meeting of persons more important or more difficult than in severe dementia. We are led, nevertheless,

¹⁸ J.C. Hughes, *Thinking Through Dementia*, Oxford, Oxford University Press, 2011, p.223-250.

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to the importance of the individual human encounter by thinking philosophically. We are back to the *simultaneous* two-way traffic. Clinical or social care practice throw up dilemmas and issues for the philosopher to ponder, amongst the most profound of which concern the ways that persons relate to each other and co-create the possibility of therapeutic spaces even in the midst of physical and mental frailty. The philosopher's answer to these dilemmas, in terms of an account of the nature of personhood and the inevitability of the human person perspective, is already realized in the actual encounters of clinicians and others in the health and social care fields, so that philosophy and practice are simultaneous. There's no dementia care without philosophical relevance and there's no philosophical relevance in the absence of embodied dementia care. The philosophical relevance is implicit in the acts of dementia care.

I shall now turn to consider a particular philosophical argument to show its relevance to dementia care. I have chosen a somewhat abstract argument about normativity, an argument that stems from the philosophy of thought and language, in order to show how even idiosyncratic arguments about meaning turn out to be relevant to practice and to dementia care.

Normativity and psychological states

I shall present here an adumbrative account of the nature of the normativity of intentional psychological states, which I have discussed in more detail elsewhere (Hughes 2011, pp.81-116)¹⁹, but which also draws upon arguments set out by Thornton (2007, pp.123-164)²⁰. The argument has four steps:

- Intentional psychological states are normative;
- Normativity can be thought of as rule-following;
- Rules and rule-following involve practices and customs;
- Practices and customs are embedded in the world.

Normativity and intentional psychological states

Wittgenstein's famous account of rule-following seems to be motivated by concerns around the problem of intentionality as it relates to understanding (Wittgenstein 1968, §138-242)²¹. Intentional mental states are *about* something. When I understand, my understanding is *about* or *of* something. Hence, when I say 'Now I understand' I am committed to certain things being the case, both now and

¹⁹ J.C. Hughes, *Thinking Through Dementia*, Oxford, Oxford University Press, 2011, p.81-116.

²⁰ T. Thornton, Essential Philosophy of Psychiatry, Oxford, Oxford University Press, 2007, p.123-164.

²¹ L. Wittgenstein, *Philosophical Investigations*, §138-242 (eds. G.E.M. Anscombe and R. Rhees, trans. G. E. M. Anscombe), Oxford, Blackwell, 1968. (First edition 1953; second edition 1958; third edition 1967).

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in the future. I grasp something 'in a flash' that will constrain the future (Wittgenstein 1968, §138)²². Wittgenstein asks how can all future uses come before my mind when I understand the meaning of a word or phrase? There is a trivial sense in which the use of concepts is always normative. It is trivially true that "table" refers to the table and not to the chair. Intentional psychological states, however, such as my understanding the meaning of a word, involve further commitments. If I say 'I understanding arithmetic', for instance, the mental state of understanding determines something, namely what must be the case when I am faced by an arithmetical problem. Uniquely, intentional psychological states connect with and constrain the actual instances that justify my saying I understand, intend or mean something, even when the instantiations of these claims are in the future. What, therefore, are the standards of correctness or incorrectness that allow us to say that someone has or has not understood X correctly, given that we do not yet know (short of being able to see into the future) whether or not the person has understood? Of course, it is not all about the future: the temporal relationship is not crucial. But being in a mental state normatively constrains the world because, 'in a flash', (when I grasp the meaning of a word or understand the arithmetic) something extended over time, my grasp of the meaning or my understanding of arithmetic, comes into being. Intentional psychological concepts, which stand for mental states, set up normative links between both the mental states and the circumstances in which the normal expression of the concepts occurs.

It is a crucial point that the normativity relevant to intentional psychological states is constitutive. Luntley puts the point this way:

'The normativity of content means that understanding the meaning of an expression requires that you grasp certain patterns of use. These are patterns of use that you have to grasp if you understand the concept. ... Understanding the concept places certain obligations upon the speaker to use the concept in a patterned manner' (Luntley 1999, 16)²³.

Intentional psychological states, therefore, involve normativity as a constitutive feature. A particular mental state (e.g. understanding, intending or remembering) involves the norms that govern whether or not the mental state can be assessed as correct or incorrect, even if those norms will be realized in the future.

The rule-governed nature of normativity

Wittgenstein highlights the suggestion that intentional psychological states are constitutively normative by an analogy with rules. Rules constrain: it is

²² Wittgenstein, Philosophical Investigations, §138.

²³ M. Luntley, *Contemporary Philosophy of Thought: Truth, World, Content*. Oxford UK and Malden USA, Blackwell Publishers, 1999.

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constitutive that they should do so by establishing norms. We can think in much the same way, according to Wittgenstein, of psychological phenomena. Thus, understanding how to complete an arithmetical series just is the ability to apply the arithmetical rule. Moreover, this feature of intentional psychological phenomena is generalizable. Wittgenstein famously says:

'A wish seems already to know what will or would satisfy it; a proposition, a thought, what makes it true – even when that thing is not there at all! Whence this *determining* of what is not yet there? This despotic demand?' (Wittgenstein 1968, §437)²⁴.

To summarize, intentional psychological states are normative. It is constitutive that they constrain how the world will be. They constrain things in the way that rules do. To understand normativity, therefore, requires an understanding of the nature of rule-following.

Wittgenstein's account then turns to consider various ways in which we might try to grasp something in a flash (a rule say) which then constrains the future. But, in negative mode, he rejects a number of possibilities. He rejects the metaphysical claim that there could be platonic rails to guide our meanings, understandings and so forth. He rejects the idea that there are mental or causal processes going on to underlie the mental phenomena. Wittgenstein also rejects a deeply sceptical challenge to the idea that rules will be helpful. Summerfield (1990) summed up the challenge in this way: 'various interpretations of a linguistic sign are *always* possible'. The worry is that there will be a regression which cannot be stopped:

"... if rules are to guide our actions, and so on, the linguistic expressions by which we represent them to ourselves need to be interpreted, and we cannot fix the interpretation merely by producing more linguistic signs that themselves require interpretation, or we launch the regress" (Summerfield 1990).

What is required, therefore, is a way to meet the sceptical challenge. The answer is to see rules as practices.

Rules and practices

The rule-following considerations in Wittgenstein recognize the normativity of intentional psychological concepts. Wittgenstein asked:

"... what kind of super-strong connexion exists between the act of intending and the thing intended? – Where is the connexion effected between the sense

²⁴ Wittgenstein, *Philosophical Investigations*, §437.

²⁵ D.M. Summerfield, "On Taking the Rabbit of Rule-Following out of the Hat of Representation: A Response to Pettit's "The Reality of Rule-Following"", *Mind*, 99 (1990) 425-31.

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of the expression "Let's play a game of chess" and all the rules of the game?' (Wittgenstein 1968, §197)²⁶.

He responded:

'Well, in the list of rules of the game, in the teaching of it, in the day-to-day practice of playing' (Wittgenstein 1968, §197)²⁷.

If I intend to play chess then I must be familiar with the whole enterprise of chess-playing. We have to consider the full context of chess-playing to understand the connection between intending to play and actual playing. This inevitably involves the use of rules. The answer to the problem raised by intentionality is to be found in the day-to-day practices, which are part and parcel of our use of these concepts. As Wittgenstein said, 'the meaning of a word is its use in the language (Wittgenstein 1968, §43)²⁸. And another way to put this is to say that, as in playing chess, in order to understand meaning we must be able to participate in the particular practice. To understand is precisely to be able to do this thing and to know that it is *this* and not *that* which counts; *this* is constitutive of the understanding. Wittgenstein puts it this way:

"...there is a way of grasping a rule which ... is exhibited in what we call "obeying the rule" and "going against it" in actual cases' (Wittgenstein 1968, §201)²⁹.

To be able to follow a rule or to understand something, therefore, involves grasping practices. The next step in the argument is to understand something further about practices, which have to be characterized in such a way as to prevent a slide into scepticism.

The embedding of practices

It was Kripke³⁰ (1982) who highlighted the 'sceptical paradox' described above by Summerfield (1990)³¹. He then provided a 'sceptical solution' which was firmly based on a communitarian view. It is, on this view, communal practices that set a standard of rightness or wrongness, that is, which establish the normativity of intentional psychological states. One possible response to the community view is to say that it is just as easy to be sceptical about the community as it is about the individual.

²⁶ Wittgenstein, *Philosophical Investigations*, §197.

²⁷ Wittgenstein, *Philosophical Investigations*, §197.

²⁸ Wittgenstein, *Philosophical Investigations*, §43.

²⁹ Wittgenstein, *Philosophical Investigations*, §201.

³⁰ S. Kripke, Wittgenstein on Rules and Private Language: An Elementary Exposition, Oxford, Basil Backwell, 1982.

³¹ Summerfield, "On Taking the Rabbit of Rule-Following out of the Hat of Representation: A Response to Pettit's "The Reality of Rule-Following"", 425-31.

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An alternative account of practices is the constructivist view, according to which practices involve people deciding as they go along. This gives us a different picture of normativity as akin to a disposition. Wright, who put forward this view, says in connection with when it might or might not be licit to use the word "green":

'All that I can effectively intend to do is to apply "green" only when it *seems* to me that things are relevantly similar; but that is not a commitment to any regularity – it is merely an undertaking to apply "green" only when I am disposed to apply "green"³² (Wright 1981, p.37).

Elsewhere, Wright suggests that we are, 'the perennial creators of our concepts, not in the style of conscious architects but just by doing what comes naturally' (Wright 1986, p.294)³³. The emphasis here is on natural dispositions to respond in certain ways. One worry about this view of how practices supply normativity is that it seems to get rid of the possibility of correction by others. We can simply point to our natural dispositions without the possibility that they might have led us astray. For McDowell this is unacceptable:

'... the denial of ratification-independence ... yields a picture of the relation between the communal language and the world in which norms are obliterated' (McDowell 1984)³⁴.

Elsewhere I have summarized the problems of these accounts of practices in this way:

The community view makes normativity a consequence of practice and constructivism makes it a matter of on-going practice constrained by human nature. Both accounts link normativity to practice, but a problem remains: from how we actually do act, it may seem that we cannot derive how we ought to act. From the fact that, when I say I understand the formula, I intend 1004 to follow 1002, it does not follow that this must be so for me the next time, nor for someone else who understands the formula. Practice in itself does not provide the forceful account of normativity required to understand intentional psychological states. Something more is required to make practice sufficiently robust to carry the normative commitments of intentional psychological phenomena'35 (Hughes 2011, pp.102-103).

If practices were only a matter of human agreement or human disposition, then normativity seems either contingent upon practices or a consequence of them. The embedding of practices in the world is a means to secure their normativity. Practices have to be seen as part of the world. They just are features of the world

³² C. Wright, Wittgenstein on the Foundations of Mathematics, London, Duckworth, 1981, p.37.

³³ C. Wright, "Rule Following, Meaning and Constructivism", in: C. Travis (ed.), *Meaning and Interpretation*, Oxford, Blackwell, 1986, p.294.

³⁴ J. McDowell, "Wittgenstein on Following a Rule", *Synthese*, 58 (1984) 325-363.

³⁵ Hughes, *Thinking Through Dementia*, p.102-103.

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with which we must live. This is not to say that they cannot be modified, but they are held in place by other features of the world, which will be more or less open to modification. Some things will not shift.

Normativity must already reside in the practices for them to have the features that we require, namely that these norms of practice are not open to human disposition or convention, and so on. This normativity is a condition for the possibility of there being the concepts that we use and the meanings which we convey. Without it our concepts and meanings are open to the sort of sceptical challenge we discussed above. Normativity, on this view, is a transcendental feature of intentional mental states: it is constitutive of such states that they should normatively constrain what will and will not be in accord with them. The normativity is also immanent. It does not come from elsewhere. It is a feature of the world of human beings who understand mental states in this way. It is also something that cannot be reduced or explained further.

In coming to understand intentional psychological states, therefore, we see that normativity is to be understood transcendentally as a condition for the possibility of these states being the states that they are; but we also see that it is constitutive, immanent and irreducible. These practices are deeply embedded in the world. The normativity that results from this understanding in terms of practices is just a feature of the world that cannot be analysed further. It sits there as part of the fabric of our world. It reflects a form of life in which words are used in this way because the world is as it is for us as human beings.

Dementia-in-the-world

Where does this take us? It means that when we try to give an account of dementia, which must include an account of how cognitive functions are affected, we must give an account that allows room for these features of intentional psychological states: that they are normative in a manner that is constitutive, immanent and irreducible. In *Thinking Through Dementia* ³⁶ (Hughes 2011) I argued that the current models used to understand dementia, whether biomedical, cognitive or social constructionist, did not give an adequate account of intentional mental states. Indeed, I went further and suggested that no models will be good enough, because they will always be only approximations. We need a world of real human engagement, one without models, where people meet in flesh and blood. Dementia is deeply embedded in the world on this view: it is part and parcel of the world that our brains age and that our cognitive functions change. Evaluative judgments are required to determine where normality ends and pathology begins. But any account of memory that does not allow it to be regarded as something for which there are criteria of correctness, that is, norms governing its correct usage,

³⁶ Hughes, Thinking Through Dementia.

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which must be independent of personal fiat or community agreement, will be insufficient. Remembering is a matter where there can be correct and incorrect accounts and this is not governed by biomedical concerns, nor is it decided on the basis of cognitive neuropsychology, nor even by a process of social construction. To remember is to be able to participate in a practice of correct and incorrect instances of remembering, but these instances and the criteria of correctness are deeply tied into the world. The normativity around remembering is constitutive, immanent and irreducible – it is not a matter of anything else. It is simply part of the fabric of the world.

Dementia, then, has to be seen as deeply embedded in the world. But we must understand the world – our human world – as being very broad. Understanding dementia, therefore, is always to understand dementia-in-the-world. It is to understand a particular person within a particular context, where that context ranges from the person's genetic endowment to the setting of his or her family, to the immediate environmental factors and cultural issues that might be of concern, and on to spiritual dimensions of care. Dementia-in-the-world is always about individuals in relationship with their own histories and with the bio-psychosocial and spiritual aspects of their lives, as well as with the cultural, moral and legal surroundings and so forth, which govern their relationships with others and with the world.

Heidegger's notion of being-in-the-world (Heidegger 1962)³⁷ conveys both the manner in which we find ourselves in the world – it is not something we have a choice over – and the manner in which we relate to other things: they are part of our world; we stand in relation to them. In particular, we stand in relation to other human beings in the world in a unique manner. Whereas we have concern about other things in the world, so that our being-in-the-world is characterized by a type of "care", our relationships with other human beings is one of solicitude. The notion of dementia-in-the-world is similarly meant to convey how dementia must be viewed. It can be viewed as something we must conquer; but it can also be viewed as something we must live with. It is and is not part of our being inasmuch as it is and is not part of ageing or, quite simply, living.

It all depends on what we mean by "dementia" in the first place. As an organic disease of the brain it is something we do well to try to prevent and treat if we can. As forgetfulness and mild cognitive impairment it is maybe something we should live with. There is a significant tension between these two thoughts, but that is a manifestation of the standing of these phenomena in the warp and woof of human life. Dementia-in-the-world has to be seen broadly, where biological changes are seen alongside evaluative judgments and psychosocial determinants of disease.

³⁷ M. Heidegger, *Being and Time* (trans. J. Macquarrie & E. Robinson), Malden MA, Oxford and Carlton (Australia): Blackwell, 1962). First published as *Sein und Zeit* in 1927.

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Dementia-in-the-world, therefore, should elicit our deep solicitude. We are interconnected. The dementia of the Other is my dementia too: if I am to live authentically I cannot ignore it. Indeed, this is no different from any other condition that affects humankind, except that dementia affects aspects of the self in a particular way. Nevertheless, the ubiquitous threat and challenge posed by dementia means that compassion – the ability to suffer with – should be a natural reaction. Our solicitude should bind us together in a type of solidarity (Nuffield Council 2009)³⁸. Dementia affects us all in one way or another. Solidarity requires a societal response. People with dementia are still citizens who should enjoy the rights and respect inherent to citizenship. Dementia-in-the-world is a device to emphasize the complexity of the standing of people with dementia as beings of this human type thrown into the multifarious ways of existing qua human beings. And, in addition, dementia-in-the-world suggests the importance of our interactions on the basis of our inherent interconnectedness and interdependency, which must reflect both our sense of solidarity and our natural solicitude for other human beings.

The view of dementia encouraged by the notion of dementia-in-the-world is a broadening one: it refuses to be reductive; it looks to the thing in itself, acknowledging the impossibility of fully encompassing that which it is, but in the hope of shedding light on it; it embraces the world as a constitutive feature of dementia; it gives a perspective on the surround, on the notion of Being-with, on the need for solidarity ...'39 (Hughes 2011, p.218).

Conclusion

The relevance of ethics and moral philosophy to dementia care is quite clear. But in pursuing this I think I have shown how ethics cannot simply rest at the level of principles and guidance. Ethical reflection raises philosophical concerns. In addressing such concerns we get a feel for the simultaneous two-way traffic between philosophy and practice. For, the reality of practice, in which we co-create spaces of meaning, is deeply philosophical. And it is deeply philosophical because of the nature of personhood, which underpins many of our ethical concerns.

When we turn to a subject that seems more abstract and abstruse, such as the normativity of intentional mental states, there is a similar conclusion. It transpires that normativity is maintained in the world as a constitutive, immanent and irreducible feature of the practices that make up the world, that is the human world. Seeing our mental states as deeply embedded in the world demonstrates to us that mental problems are not to be viewed too narrowly, but must be understood

³⁸ Nuffield Council (2009). *Dementia: Ethical Issues*. London: Nuffield Council on Bioethics. Available at http://www.nuffieldbioethics.org/dementia [last accessed 24th May 2014].

³⁹ Hughes, *Thinking Through Dementia*, p.218.

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broadly in the context of a broad understanding of what it is to be a person. The human person perspective on the world is one that is not circumscribed: it brings in everything that might be relevant for the individual.

Philosophical reflection is relevant, therefore, because it broadens our view of the world. As a consequence, from the human person perspective, dementia becomes dementia-in-the-world, where nothing is ruled out as irrelevant, where the biological approach is taken seriously, but so too are the neurocognitive, social, spiritual and aesthetic approaches. In dementia, our being as human beings is critical. Philosophy can lead us to consider our being-in-the-world and the implications of this for clinical practice. In a sense, the relevance of philosophy is that it can reveal to us afresh the relevance of clinical practice as a human and human endeavor.