

## Putting it all together: so what?

### Introduction

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A challenge, alluded to in Chapter 1, put to all the authors in this book series is to answer the question ‘So what?’. What does all that has appeared in this book mean for people living with dementia, their families, people working in dementia care, policymakers, professionals, community activists and so on? In Chapter 1, I said that ethical questions are ethically imperative and that we should be ethically and morally energetic.

Part of me wishes to reject the ‘So what?’ question: if someone cannot see that an ethical response is required by the realities of dementia and dementia care – a response that takes seriously questions about what is morally right or wrong, good or bad – it would be like trying to play tennis with someone who simply did not recognize the rules of tennis. It should be obvious that we need thoughtful answers to questions such as: Does everyone need to be told their diagnosis? Should people with dementia drive? Would it be right to use robots to care for people living with dementia? Shall we use a feeding tube for this person with advanced dementia who now chokes when eating?

Still, it is useful to ask, ‘So what?’. For one thing, as I suggested in connection with the discussion of patterns of practice in Chapter 6, most practitioners simply get on with the job without the ethical issues ever becoming obvious, although they lurk beneath the surface of practice. To put it another way, the questions to which thoughtful answers are required are often not even asked.

Throughout the book I have suggested ways in which the discussion has been relevant to the different groups involved in dementia care, including families and people living with dementia themselves. I now suggest that the implications of a book that reconsiders ethics in dementia care can be further considered at three levels: first, there are the implications for ethics itself; secondly, there are the implications for people living with dementia and for their families and (informal and formal) carers; thirdly, there are implications for the *polis*, the body politic, mentioned in Chapter 13, which would include policymakers, those who provide services and activists.

## Implications for ethics

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The implications for ethics are general and specific. The general implication stems from the vulnerabilities associated with dementia. This includes the cognitive vulnerabilities, but the physical and emotional vulnerabilities too. (Incidentally, Behuniak (2010: 238) argued that dementia care requires a 'theory of vulnerable persons'.) In particular, it is the implication that stems from dependence.

Traditionally in clinical ethics and bioethics, dependence would be seen as the antithesis of autonomy and the loss of autonomy would be seen as potentially catastrophic for the person living with dementia. As we saw in Chapter 8, however, our autonomy is always dependent on outside support. If this is more so in dementia, it is a matter of degree and it does not change in any fundamental way how we should see and treat people with dementia. To quote Agich: 'The concept of autonomy properly understood requires that individuals be seen in essential interrelationship with others and the world' (Agich 2003: 174). The general implication when we reconsider ethics and dementia is that respect for autonomy as a principle needs to be replaced by respect for relational autonomy. The person living with dementia must always be seen in a context of relationships, but interdependence and interrelationships are what characterize us all as human beings. Our judgements – of any sort, but chiefly here our ethical and moral judgements – about people living with dementia should be as judgements about anyone: they should seek to understand the perspective of the person most concerned, where this perspective will involve that individual's historical, societal, cultural and personal viewpoint.

The more specific implication for ethics to emerge from this book concerns the notion of patterns of practice. The value of this approach needs to be considered in more detail, with a more critical eye. But these pages have at least confirmed that there is some merit in pursuing its explanatory and determinative functions. It reflects – it explains – real life ethical decision-making, whereby we decide reflexively in line with the patterns of practice that instinctively shape our lives. It can also be used to determine how we think about ethical issues, how we determine what is right or wrong, good or bad, by focusing our attention on the requirement that our actions, decisions and thoughts should show internal and external coherence.

Internal coherence was conceived as meaning both within practice coherence and coherence within the individual's practice. But I suggested this was akin to casuistry (Chapter 3); and, similarly, I suggested that external coherence was akin to virtue ethics (Chapter 5). Neither of these alignments was random. The immersion in the particularities of the case and subsequent interpretation required by casuistry (Murray 1994: 96–99) in order to judge whether or to what extent the current case is similar to some sentient case is of a piece with the demand for internal coherence. The sentient case will be drawn from the person's own collection of cases, which opens up the possibility of

self-deception. I may think that the way I do things is right, but I may be way off the mark. Hence there is also the requirement for external coherence in line with virtue ethics.

Why virtue ethics? Well, there are established arguments against both utilitarianism and deontology, the other major contenders, even if they have their uses in certain circumstances (Williams 1972: 96–112; Raphael 1981: 43–66; MacIntyre 1985: 43–47, 70–71, 198–199; Hursthouse 1999: 52–55). About utilitarianism, for instance, Raphael (1981) wrote: ‘Where utilitarianism goes wrong is in fastening upon the estimation of amount of happiness as such, instead of viewing the concept of happiness as subordinate to that of a person. Happiness is important for ethics because it is the chief aim of persons’ (p. 54). Beauchamp and Childress (2001: 354–355) record three problematic areas for Kantian deontology: first, there is a significant difficulty where obligations conflict (if you have a duty to provide healthcare to two people who are indistinguishable from the point of view of their illnesses, but you can only attend to one of them, how do you decide between them?); secondly, Kantianism seems to over-emphasize the law and underplays the importance of relationships, which are so relevant to dementia care; and thirdly, Kant’s view of the moral life is too abstract and formal, without practicability.

Of course, criticisms are also levelled at virtue ethics (Hope et al. 2003: 10; Oakley 2007: 90–91; Bloch and Green 2021: 5). But it is difficult to dispute the idea that we should aim to become the best that we can possibly be. Why should we not? This is not to say that we should all be saints. It may be that I am quite limited by a variety of genetic and social factors in terms of what I can achieve, but does this mean that it is good for me to aim to be bad and to do the wrong thing? How do we know what it is to be good and to do the right thing? Well, the virtue words tell us. Who would wish to be mean, hubristic, imprudent, treacherous and so forth? Aristotle used the word *eudaimonia* to describe the good at which human beings should aim. This has been translated as ‘happiness’ but is better understood as ‘human flourishing’ and it is cashed out in terms of the virtues. As MacIntyre (1985: 148) has said:

Human beings ... have a specific nature; ... they have certain aims and goals, such that they move by nature towards a specific *telos*. ... The virtues are precisely those qualities the possession of which will enable an individual to achieve and the lack of which will frustrate his movement toward that *telos*.

It seems commonplace, therefore, to suggest that our patterns of practice should cohere with the natural aims and goals of human beings, which is to say that there should be coherence with the virtues. In my view, virtue ethics has enough resilience to deal with conflicting virtues, to justify particular courses of action and to allow a rational account of our decisions (Hursthouse 1999).

Patterns of practice allow us to describe and explain our decisions, actions and thoughts. A feature of such descriptions and explanations, however, which

is another implication of this book (derived from the ethical approaches discussed in Chapter 4), is that frequent reference will be made to the narratives of those involved, that caring and solicitude will have prominence, that there will be 'the active creation and recreation of meaning and identity' along with 'the negotiation of empowerment' (Lyman 1998: 55) and that authentic dialogue will characterize the interactions of all those concerned.

## **Implications for people living with dementia and for those who care for them**

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Perhaps shockingly, I have little to say about the implications for all those concerned with dementia care. Also shocking, perhaps, is that I have lumped together under this heading both people living with dementia and professionals, such as psychiatrists and neurologists, along with all those other formal and informal carers, including families. Is this not a mistake? Are not the implications for people living with dementia very different from those that affect the specialist physician?

Of course, all of these people have different challenges and tasks. Struggling to make a cup of tea and struggling to make a diagnosis of dementia with Lewy bodies are very different things. But they are both important struggles and my suggestion is that they have something of crucial importance in common. The thing of importance is the implication of these pages that I would wish to present to all these varied groups of people. The implication, however, is by no means new. It is straight from Kitwood (1997a): 'the person comes first'.

I take seriously the wise warning issued by Baldwin and Capstick (2007: 273): 'For all we owe to Kitwood's work (and the debt is considerable) it may, in some ways, be time to come out from his shadow'. We can criticize Kitwood – as I have done (Hughes 2019) – and there is certainly no need to feel hide-bound by his work. His work was wide-ranging in many ways, but there was a definite focus on the inner psychology of the person, despite the social spin. Talk of citizenship and human rights, of power relations and politics, indeed of the important socio-cultural context within which dementia care takes place, is (except tangentially or in passing) absent from Kitwood's work (Baldwin and Capstick 2007: 184–186). For instance, Baldwin and Capstick (2007) suggest that 'because personhood is essentially an apolitical concept it does not provide the language for discussing people's situation in terms of power relations' (p. 184). They also say: 'the challenge will be to move beyond personhood while simultaneously retaining a focus on it' (p. 186).

I think this is spot on. Well, almost! My quibble is that I see no reason to 'move beyond' personhood, partly because, for instance, stubbornly I see no reason to regard personhood as 'essentially an apolitical concept'. If we return to the notion of the person as a situated embodied agent (Hughes 2001), why would the person not be situated in the *polis*? How can I, qua

person, avoid being political, even if only in the minimal sense that I live in a state that is governed? Even if I were stateless, as many people are, this is itself a political issue.

In this book I have stressed that even mundane decisions in health and social care have an ethical component. In Chapter 2, I argued that politics is ethics writ large: it is the public expression of our private ethical beliefs. For the concept of personhood to be apolitical it would also have to lack all moral content. But it does not. For we are inherently ethically situated. Part of what it is for us to be the persons that we are is that we care about things, we have values, there are things of importance to us. In saying this I am reflecting the work of Charles Taylor (1989: 34): 'What I am as a self, my identity, is essentially defined by the way things have a significance for me. ... we are only selves insofar as we move in a certain space of questions, as we seek and find an orientation to the good'. Or, as Schneewind (1991: 422) wrote in reviewing *Sources of the Self*, 'The self, on Taylor's view, is not an objectively given entity like a star or a bacillus. Its identity is constituted largely by its values'.

My point is that we should not 'move beyond' personhood but expand it. Or rather, see that it is an expansive notion. We need a broad view of personhood, what I have referred to as 'the uncircumscribable human-person-perspective' (Hughes 2011b: 241–249). Then the point is, not that this remains a detached theoretical construct, but that it is a reality in all of our dealings with persons, including with persons living with dementia. This individual in front of me in this care home is someone of value, who also has values, who may to a greater or lesser extent be able to signal what is of personal significance, concerning whom our judgements now about whether or not to start a medication are inherently ethical in nature, and probably arise because of economic decisions by the management of the chain of care homes concerning levels of staffing, but whose placement in this home reflects a socio-cultural crisis in the family, which in turn stems from political decisions about the provision of care in the community. And so on.

To be the person that I am is for me to have a history, but it is also for me to have (amongst many others) moral and political orientations, even if these are sordid and ignominious; and even if they are unrecognized by me. The notion of personhood, therefore, is deeply rich. But so too are real people. One of the great privileges of being a clinician or carer of any sort is to learn so much about the personal lives of the people we serve and care for: to see into their histories, into the dramas of their lives and families. Reflection should also help us to see that we stand in relationship to the person as part of a bigger socio-cultural and political framework. But these larger frameworks and discussions within the broader perspectives relevant to personhood are always, at root, about a particular person or persons. In the UK, when the Prime Minister announces a new grand scheme to revitalize the country, how often does the Leader of the Opposition retort by pointing to the deprivation that will still be suffered by a particular constituent? Politics seems to be about the big picture, but in reality it is about individual lives and people.

The person, therefore, still comes first (Kitwood 2019). Kitwood's conception of personhood was profoundly experiential and relational, it was about psychological well-being and about embodiment, but it was also social and organizational. If he did not pursue some of these topics far enough and if he did not go beyond them to offer a picture of the person as a citizen and as a bearer of rights, so be it. But this does not mean that personhood itself is confined. To think so would indeed be to live under Kitwood's shadow and to be hidebound by his work.

The person living with dementia may wish to demand a right to be heard; the family member may wish to advocate for the person whose communication is impaired; the carer in the nursing home may wish to spend some time brushing the resident's hair; the social worker may wish to work harder to find funding; the GP may wish to take some time to listen to what the person living with dementia is saying; and the psychiatrist may wish to encourage a psychosocial approach to the management of the behaviours that some are finding challenging. These are all the sorts of ethical responses that, I hope, would emerge from understanding the lines of reasoning suggested in this book. But they are all based on the implication that *the person comes first*. Arguments about citizenship and rights are only of value because they are, first and foremost, arguments about real people who, *as persons*, are citizens and human beings embedded in the *polis*.

## **Implications for the polis**

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So, what are the implications of this book for those who make up the body politic, for the activists, the policymakers and politicians? In Chapter 13, there was an implicit movement from personhood to citizenship and then to rights. All of this is to the good. What I have said above, however, may seem contradictory. Because now I wish to suggest that we also need to move back to person-centred care. Or, at least, back to the idea that personhood and the person come first.

My point is this: that citizenship is a function of personhood; and that rights reflect the ethical standing of persons. The person comes first.

It is perhaps useful to turn our attention to the whole question of rights, since the cutting edge of theorizing about dementia encourages a rights-based approach. As we saw in Chapter 21, there is the suggestion that in contrast to citizenship models, 'Human rights ... transcend political and/or social boundaries by virtue of their universality, albeit to be recognized and implemented at the local citizenship level' (Grigorovich et al. 2019: 177). I had the temerity to suggest that there was some flag-waving here in favour of human rights. For one thing, it is noteworthy that human rights have to be 'implemented at the local citizenship level'. Just so; and at the 'citizenship level' they have to be implemented by individuals, person to person. The global

proclamation of a right is a glorious thing, but empty without personal endeavour. My belief (expressed in Chapter 9) is that fundamental human rights do reflect something radical about how we should engage with each other in the world. Once rights are established, the person has protection (at least in theory) under the law; and United Nations conventions, such as the CRPD, help to encourage support for those who claim rights. As I suggested in Chapter 13, the assertion of rights for people with dementia seems crucial and certainly relevant in connection with forced care (Chapter 22), sexuality and intimacy (Chapter 23) and in the time of pandemic (Chapter 27). Nevertheless, in Chapter 13, I also suggested there are conceptual limitations to claims about rights.

We might wish to argue that there are no such things as human rights. A right can be defined as ‘the capacity to exercise a certain choice with institutional impunity’ (Pettit 1980: 77). If you have a right to freedom of expression, no one can stop you from saying or writing or in any other way expressing yourself. However, according to a thinker as formidable as MacIntyre (1985), ‘... there are no such rights, and belief in them is one with belief in witches and in unicorns’ (p. 69). He is not talking about rights given to certain specified groups by law or custom, but of so-called ‘natural’ or ‘human’ rights: ‘... those rights which are alleged to belong to human beings as such and which are cited as a reason for holding that people ought not to be interfered with in their pursuit of life, liberty and happiness’ (pp. 68–69).

Nevertheless, laws – such as the *Human Rights Act 1988* (Home Office 1998) – can establish rights, even if they cannot be given further metaphysical underpinnings. If by custom and practice we elect to say that every innocent person has the right to life, then they do, even if that right cannot be proven to exist other than by its instantiation in law. (MacIntyre (1985: 69) denies that the assertion of such a right cannot be shown to be self-evidently true for instance.) Exactly what such a right entails, who counts as an ‘innocent person’ for instance, will be established by argument and precedent in the courts.

What I take from this is that there are legally established rights to which we can appeal, and we can argue about exactly what might count as falling under the description of such rights, but we should be chary of waving the rights flag willy-nilly. Instead, the person comes first. Mostly, I should be treated respectfully and courteously because I am a person. I do not have a right to respect and courteousness as such. Simone Weil (1909–1943) wrote that the notion of obligations (or duties) was prior to that of rights. It is only once the obligation is recognized that the right becomes effectual. Hence, she wrote: ‘An obligation which goes unrecognized by anybody loses none of the full force of its existence. A right which goes unrecognized by anybody is not worth very much’ (Weil 2002: 3).

She went on to say (using the gendered language of her day): ‘A man left alone in the universe would have no rights whatever, but he would have obligations’ (p. 4). Persons, as such, have duties even to themselves; but these are not

rights. The duties, to ourselves or to others, stem from our nature as persons. It might not be the most sensible thing to place more weight on rights than they can withstand.

In an interesting article on social policy and human rights, Boyle (2010: 511) started by asserting that 'Autonomy is a fundamental human right, essential for equality'. Ignoring the possibility that my right to autonomy might conflict with yours, from an ethical perspective it is certainly true that people have obligations (or duties) to respect the wish for self-determination of people living with disabilities. These can be established by thinking about what it is to be a person (to be innately interrelated and interdependent) and how we flourish as people, which we do by demonstrating the virtues of, for example, compassion, justice and respect. So, social care emanates from the standing of the person as such, not from a right as such. To assert one has rights is the obverse of such duties. To do so is a political act, but one that is empty without the ethical obligations of friendship and love which stem from personhood.

I note that Butchard and Kinderman (2019) were keen to push the idea of identity, which they linked to personhood. They suggested that preserving identity might enhance human rights. But if we can preserve identity, is that not enough? What do rights add to that? It makes more sense to argue that rights might preserve identity, but not without other things being in place which do not, after all, require rights. They said, 'There is no obligation to carry out person-centered care other than knowing that it is the right thing to do' (p. 165); but what greater reason is there to do something other than knowing it is the right thing to do? As they reasonably argue, once something has a legal basis and framework, people will be more inclined to do it. At which point I am inclined to ask how a right to person-centred care and indeed a right to personal identity (which they commend at the end of their paper) would be translated into an enforceable law? Simone Weil, in any case, might well argue that there is an obligation to be person-centred; it comes from the nature of our personhood (Heidegger's *being-with* perhaps). Strikingly, Kitwood himself espoused a similar line to that of Weil when writing of the criteria for a model or theory of personhood. One criterion was that '... it must view the person as a social being, not as a monad... That is why a moral theory that speaks of persons and obligations is more powerful than one which merely speaks of individuals and their 'rights'' (Kitwood 1997b, cited in Baldwin and Capstick 2007: 236).

Hence, my suggestion is that the implication for reconsidering ethics in dementia care at the level of the *polis* is not to do with rights as such, nor even with our obligations, but is to do with grasping and encouraging as broad a view of the person as possible. This means including people living with dementia in every way possible, not as a matter of rights (although their rights should be respected), not because they are citizens (although they are), but because of their personhood and all that this entails (see Chapter 13). Inclusion should be at every level possible, from within the family and community to social and political involvement. This is where the importance of activists is seen; this is where it is important to involve people living with dementia in research in a

meaningful way; this is where the will and preference of people living with dementia should be honoured; this is where people with dementia should be at liberty to pursue their legitimate goals in a manner that suits them best.

## Conclusion

The broad view also suggests something much more. In an article published in the year of Kitwood's death, there are a series of fascinating statements right at the end, where he wrote that the 'ethic of context' cannot be ignored (Kitwood 1998: 33). He noted that interactions which either maintain or undermine personhood fall within the category of practical morality, but that these interactions also have 'an aesthetic dimension' (p. 33), which is not merely contingent. Drawing from the idea of authentic acting, Kitwood emphasized the requirement for 'total sincerity, on being set free from the limitations imposed by ego, and drawing freely and fluently on one's emotional resources' (p. 33). He suggested that philosophers drew too heavily on the Apollonian mode rather than the Dionysian. In other words, he accused them of being too rational and not emotional and instinctive enough.

Whether or not this is wholly fair to philosophers, interest in aesthetics and dementia is a flourishing business (Hughes 2014c). Zeilig et al. (2015) suggested that an arts-based approach might be a way to engage with staff in care homes and empower them to recognize their skills and to focus on person-centred care. Pia Kontos and John Killick have been using the arts to enable people with dementia to flourish and to reduce stigma for some years (Killick and Cordonnier 2000; Killick 2013; Kontos and Grigorovich 2018; Kontos et al. 2021b). Through co-creation, which means inclusion, people living with dementia can be as involved in an artistic process as are the professionals (Zeilig et al. 2018). Our own work has connected art, authenticity and citizenship (Hughes et al. 2021b). The links between aesthetics and dementia are wide and deep (Hughes forthcoming). But the point is that an aesthetic approach to the person – seeing the person through this lens – reflects and encourages the broad perspective of personhood, from which obligations flow. Personhood and aesthetics are intimately linked, not necessarily by human rights (*pace* Kontos et al. 2021a), but necessarily.

In the end, we need authentic solicitude which reflects our ethical and aesthetic standing as human beings in the world with all that this involves. If we could achieve this, the world would be a better place, including for people living with dementia. As Kitwood (1998: 34) wrote: 'The excellent caregiver is, so to speak, a moral artist, and sets an example to all of us as we search for the right and the good'.