

BOOK REVIEW

Julian C. Hughes. (2014). *How We Think About Dementia: Rights, Ethics the Arts and What they Mean for Care*. London: Jessica Kingsley Publishers. ISBN 978-1-84905-477-5

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Introduction

The author's aim is to suggest something about our engagement with people with dementia. We need to think about things that people say about the mind, because our memories are mental: we treasure them (if we do) in our minds. We share the view that being a person is more than just the ability to remember and thereby link up mental states. The author emphasizes two things: we are embodied and we are situated. There is an important sense in which 'to be me is to have my body'. But people are also situated in all sorts of ways that contribute to them being the person that they are, in their personal story or narrative, which links with the stories of others. People are situated in a cultural, historical, legal, social context and so on, with particular family relationships and shared experiences. All of these contexts still exist even in the midst of his severe dementia.

Hughes is clear that how we think about dementia is a matter of real concern. For if we can see dementia in the broad context of the multidimensional world, in which as minded people our lives must be understood as mutually involving, but also as biopsychosocial and spiritual realities, we are likely to adopt the right attitude towards doing something about dementia from every possible perspective because we are situated in every possible perspective, but we are also likely to see people with dementia in a better light. There are things that we can do for people with dementia, but there are also ways in which the lives of people with dementia are simply lives like any other. They will respond to joy and to laughter, to kindness and to compassion.

The conceptual framework of the volume is that our understanding of memory has a huge amount to do with our understanding of persons. For being a person, including being a person with dementia, is to be a whole lot of things, with a whole lot of ways of engaging with the world and with other people. Our engagement with people with dementia is thus a main focus of the volume.

Personhood underscores solidarity - our ethical dealings with the world of Others. Our situatedness and solidarity face us in the direction of the common good. In our encounters with people with dementia, therefore, it is in our nature to show concern and solicitude, not just as an emotional bodily reaction, but because this is who and what we are. This relies on the community recognizing, in the personhood of all its members, with or without dementia, an inherent demand for concern and solicitude. It should always have been thus. A broad view of personhood merely underpins, confirms and justifies the characteristics of a just and civilized society.

How the book is organised

The front cover illustration clearly communicates the way in which we think about dementia. It addresses: personhood, rights, ethics, the arts and what they mean for care. Here we have an example of how pictures can say more than words with three trees cut to show heads with leaves disappearing representing the loss of neurons in the person with dementia. The book is divided into five sections: Part I (Ageing), Part II (Personhood), Part III (Capacity and Incapacity), Part IV (Palliative and Supportive Care) and Part V (Arts). These themes are not confined to specific chapters and are examined from different perspectives throughout the text. Accordingly, I will not review every single chapter individually, but will focus on specific chapters to illustrate a range of points.

It is in Chapter Four, entitled "The person with dementia is the same person" that we find a seminal account of the difference between a change in personality and a change in personhood. It is still the same personality, his or her standing as a person is the same. People are a lot more than mere linked memories. If to be a person you have to be able to remember what you did yesterday, then people with dementia are not persons. We put far too much emphasis on our cognitive

abilities (being able to remember, calculate, verbally understand and the like) as the ultimate indicators of personhood. Being a person is more than just the ability to remember and thereby link up his or her mental states.

A person's bodily gestures are not just gestures perhaps: they may well carry contextual meaning and be reflections of personal autonomy. Some of the implications of this position appear clear - the views and values of the person before the onset of dementia may be relevant in making decisions, the resources that the person has accumulated during their life may be used for their benefit and family and friends may retain responsibilities and also expectations, that are normally assumed. It is because the person is definitively still a person that we must encourage and enable them to make decisions insofar as they are able and emphasize the extent to which people with dementia can still value things. But what we see here, by way of implication, is a moral imperative. It is a moral imperative to care, because we are ultimately and inherently, mutually dependent, interconnected, *human* beings.

Our experience of the world shapes our understanding of it. We see concrete manifestations of care - the daily visits of the husband or wife to see their spouse in the care home, the sensitive handling by the care staff of the bedbound patient, the attention to his or her dignity and the formal reviews that seek to protect the human rights of the individual. Caring only really makes sense if we are dealing with persons: human beings with rights and interests, whose lives have value not solely because of what they may or may not be now, but also because of their relationships and histories and because of the meaning that their lives have and have had in this context.

The person with severe dementia, for instance, is still the father of his children. He can no longer fulfil that role in the way that he once did when they were young, but the status of fatherhood cannot be taken away from him - it is a fact. It is because of this that they come to see him. They talk to him as a father, not as a stranger. They are situated in a context with him, which means that they cannot ignore his presence in the world. It may be helpful to pursue this point. Clearly, he is not like some physical object in the world that they could simply walk past and ignore.

We are not just biological bodies and our actions are not simply those of animals or artefacts; we are as Hughes rightly insists, situated. That is, we are embedded in our world - the human world - where things inevitably have a significance. They have a human significance - a significance for us - even when the meaning, of a grimace or gesture, is not entirely clear. Our situatedness in the world as beings of this sort means that we cannot simply or conveniently ignore things. Or at least, if we do, we are ignoring something of human significance so that our own status as human beings is placed in a degree of jeopardy. This does not mean that every time we ignore a gesture or grimace, or a plea for attention, we

stop being human. In fact, our status as human beings is immutable in this sense. Rather, we are not able to claim that we are leading our lives - being human beings - to the fullest extent possible. If a callous attitude towards suffering or requests for help were to become second nature - our way of being - then talk of our inhumanity would start to make sense. So our situatedness as embodied and agentive human beings characterizes our personhood.

When we move to Chapter Five of the volume, "The body in dementia", we are treated to an explanation that the stories of people with severe dementia are full of meaning, which we may or may not share. But to ignore the possibility of doing so - to fail to see their actions as significant and to fail to see our own responses as potentially conveying meaning - would be to undermine our and their standing as situated human beings. It would destroy the solidarity that should characterize our caring and solicitude. This is not the world of hypercognitivism, but the world of embodied selfhood, where the person is broadly conceived as a situated and embodied agent. This is where we grasp our experience of the world as sensual as much as it is rational. Keats famously exclaimed to his friend Benjamin Bailey in a letter in 1817: 'O for a Life of Sensations rather than of Thoughts'.

In many ways, Chapter Five moves seamlessly into the subject of Chapter Six - 'Capacity' what is it and so what? Where there is good clinical practice, such decisions are being made on the basis of a broad consensus concerning the patient's best interests (which will take into account the views of all concerned, including the expressed views of the person him or herself and significant others). But the rights of the person without capacity are not formally protected in these routine decisions about future 'placement'. Once a decision is made that someone lacks residence capacity, a whole train of events follow that might have profound consequences for the person concerned. He might find himself in an institution not of his choosing, in effect being deprived of his liberty and, thus, of a basic human right. So, huge matters hinge on the *routine* assessment of capacity and should prompt us to ask the question 'What is "capacity"?' seriously. It is equally important to establish what sort of a question this actually is. The author is not seeking a simple definition, nor is the question answered by reference to legal criteria, although it is as well to be aware of such criteria. The Mental Capacity Act 2005 defines capacity for the first time in English Law, but it does not address the issue of *what it is for the person* to have or not to have capacity. The question is about the nature of things or, more precisely, it is about what constitutes us as beings with or without these capabilities. The structure of clinical practice is generally understood to be underpinned by Law and Ethics. 'Capacity' is characterized here as an ability involving practical know-how: an ability to participate in the relevant and particular sphere of facts and value-laden acts of the human world. Capacity cannot solely be decided by reference to cognitive function tests. Decision-making will always involve

subjective and evaluative judgements, which will need to take account of the situated, embodied nature of the person's agency. Judgements about decision-making will be inherently practical, rooted in the person's ability to participate in the relevant way in the world. There are also legal implications: there is the worry that incapacity legislation will not prevent injustices. There is a need for a broad interpretation of decision-making - to involve cognitive capacity and, in addition, evaluative and volitional competencies from the situated perspective of the individual.

I is in Chapter Ten, entitled "Understanding the language of distress" that Hughes examines the tacit component of clinical judgements. One possibility is simply that we do not name the observations that go to make up the judgement that someone is in pain or distressed. In the study Hughes describes, for instance, the judgement that someone really was in pain was based not only on observation using the pain scale, but also on the person's history (derived from their notes and from nurses, carers and relatives) and on examination. Deciding that someone was in pain, therefore, as in the earlier example of bathing, depended on putting together various bits of information: not only did the person grimace, not only were the joints clearly arthritic, not only was there a history over many years of joint pain, but actual movement of the joints also produced the same sort of grimace. Perhaps in every case there are other bits of information that go together to show that the person is in pain or distressed. Perhaps at times these really are 'read' so intuitively by carers that they would find it difficult to enunciate them. Perhaps it is not just that the trouser leg goes up, but that there are also other subtle signs that go with this and are hardly noticed at a conscious level - a slight change in the vocalizations, or a slight change in the facial expression - all indicating distress. Or, perhaps carers learn things historically. Perhaps there was a time in the past when something clearly distressing happened and the trouser leg went up. Through a type of conditioning, based on closeness and intimacy, the carers have learned that this behaviour betokens distress. If pursued, this thought would suggest that all intuition is based on observation, that with enough observations, even silent ones, it would be possible to make the judgement, whether this was a judgement about pain, distress, or some other diagnosis or treatment. In the extreme, all of this could be done by a computer.

Chapter Eleven, entitled "Ethics, Patterns, Causes and Pathways: In Pursuit of Good Palliative Care", is where Hughes discusses some of the ethical and empirical issues around withholding and withdrawing treatment for people with palliative care needs and dementia. This includes considering the background patterns of practice that help us to conceptualize how we make ethical decisions. The author considers the consensus around the recommendations of the White Paper concerning palliative care for people with dementia, partly in order to draw out the ethical nature of many of these recommendations. Finally, he suggests

that we encounter each other without models and that our care pathways should be about human relationships, taking into account the breadth of such relationships and the complexity of the context in which these relationships occur, a context which involves both facts and values

The care pathway, then, as the author explains, represents a journey which is made by the person with dementia, but which is usually not made alone. The person is accompanied by family and friends, but also by professionals. Together they will be entering a terrain which involves ethical and legal, spiritual, social, psychological and biological factors. The journey will require careful navigation, as well as negotiation when values appear to be in conflict. The outcome, however, should be that the person's experience within any of these individual domains at any stage of the journey is optimal. All of this may be facilitated by tick boxes on paper or on a computer but, fundamentally, the journey is the journey of *human beings engaged with each other in the raw* with all the complexities that arise in the real world.

'The Art and Practice of memory' and 'In Praise of Negative Capability'

We arrive now at Chapters Thirteen and Fourteen of the volume. Here, Hughes makes the point that even in the presence of cognitive impairment, the person with dementia remains an aesthetic being where the possibility of interaction persists through words and poetry, through painting or pottery, or any other form of human creativity. The new culture of dementia care is a psychosocial approach, where this does not mean that the biological facts are irrelevant, but where they are not regarded as the 'whole deal', so to speak. They sit in a context, which can be characterized as essentially aesthetic. Even if we feel we must act definitively on occasions, to deprive a person of their liberty (by putting them in a nursing home against their wishes), our approach must reflect our background standing as interdependent human beings in the world, whose inherent propensity to flourish through artistic creativity should make us open to the requirement that we seek joy and beauty, not their opposites; we should seek hope, truth, love and peace. The aesthetic approach should mean that we pursue even our certainties with uncertainty, with an openness to better possibilities.

Creativity, as the author points out, can encourage authentic communication. Having a sense of the mystery of human interactions should encourage us to look at others more intensely, with a keener eye for the sparks that unite us humanly. So, too, we should listen more carefully to what is being said, to the poetry that inhabits our ways of making meaning, however impaired they might be. This is not easy in our current cultures of care, where the emphasis is on efficiency and protocols. This is far removed from 'being-with-the-Other-in-the-moment' in an authentic way.

Hughes acknowledges as key that, even in the presence of cognitive impairment, the person with dementia remains an aesthetic being where the possibility of interaction persists through words and poetry, through painting or pottery, or any other form of human creativity. Killick stands, therefore, shoulder to shoulder with the likes of Tom Kitwood (1937-1998), who emphasized the *person* with dementia and the importance of engagement with the person with dementia in a way that is reaffirming. Indeed, Killick has shown us how our approach to people with dementia can be and needs to be aesthetic. Since 1992 he has worked extensively with people with dementia, in a revolutionary manner, his work has shown us that there is 'another way'. We can progress by intuition, despite uncertainties. We can progress by leaving behind our rationality and by taking risks in our meetings with others.

The concluding chapter of the volume focusses on "Care - Solicitude and solidarity". Our solicitude and solidarity should mean that we wish to do things *now*, which will involve both a call to individual action as well as a call to political action. Hughes is clear that if people with dementia find it difficult to respond to the world in any way that seems enthusiastic or hopeful, it may be this is because we do not take the risks we should in order to engage with them in a manner that is facilitating. This is a matter of commitment. We know what can be achieved occasionally, but only political and individual commitment will produce the right sort of responses on a larger scale. This will require, however, both a broad view of the problem and a broad view of the potential solutions.

If solicitude can be seen as an existential manifestation of *angst*, it can also be seen as a symptom of hope. Our being-in-the-world is eased by the solicitude of others and by our own solicitude we make the world a better place. Solidarity, meanwhile, helps to build up the stock of good nature in the world through its practical demand for solicitous and careful action. And solidarity and solicitude together require that we pay each other closer attention in our *being-with*. Taking more notice, being empathic understanding, seeking out, representing others - these are ways in which we show both our solicitude and solidarity.

By seeking what is true in our encounters we see that this is also something beautiful. We have an aesthetic sense of our place in the world with others and through art, or other manifestations of human beauty, the nature of our solicitude is apprehended as something shared. Care is a political matter: it emanates from our standing in the *polis* as persons amongst persons, but it is also a feature of political life itself that it should strive for the common good. There is a right to care and a duty, but these come from our way of being, which includes many other aspects of our lives: our needs, our values, our hopes and our anxieties. They are non-negotiable features of our lives. Solicitude, therefore, is a prerequisite of solidarity, but solidarity is predicated on our solicitude.

Conclusion

Our solicitude and solidarity should mean that we wish to do things *now*, which will involve both a call to individual action as well as a call to political action. If people with dementia find it difficult to respond to the world in any way that seems enthusiastic or hopeful, it may be that this is because we do not take the risks we should in order to engage with them in a manner that is facilitating. This is a matter of commitment. We know what can be achieved occasionally, but only political and individual commitment will produce the right sort of responses on a larger scale. This will require, however, both a broad view of the problem and a broad view of the potential solutions. We should recognize that our situated nature means that nothing is ever lost completely. Things persist in the memories of those around us and our nexus of narratives, even if there are losses. Ageing and dementia might bring decay of one sort or another and yet, to quote William Wordsworth:

... the wiser mind
Mourns less for what age takes away
Than what it leaves behind
(from *The Fountain*, Wordsworth 2000, p.139)

The quality of this book is seen in the relevant use of quotes from the poets John Keats (1795-1821) and William Wordsworth (1770-1850) who are able to step into another's life and demonstrate greater empathy for characters. Tom Kitwood (1937-1998) was a pioneer in the field of dementia care. He developed innovative research projects and training courses, challenging the "old culture of care". His aim was to understand, as far as is possible, what care is like from the standpoint of the person with dementia. The case studies clarify the otherwise difficult concepts of dementia and 'capacity'.

Target Audience

The author anticipates that many people reading this book will be involved - family, as close friends or as professional carers of one sort or another - with people with dementia and some may be people living with dementia. It is definitely an inspiring, encouraging book for people with dementia as it goes beyond the narrow biological definitions generally used to define the condition. This author shows readers how to focus on the person and not the biological label. This unique text clearly clarifies thinking about dementia and is an invaluable resource for relatives and providers of dementia care services. Accordingly, it is highly recommended.

Conflicts of Interest

The author declares no conflict of interest.