

GUEST EDITORIAL

The aesthetic approach to people with dementia

Introduction

The question I wish to consider is: how do we approach people with dementia? I want to suggest that the approach we take should be the aesthetic one. I shall need to say what this is. My question is not an empirical one. I am not asking how we *actually* approach people with dementia. My question has an ethical bent to it: how *ought* we to approach people with dementia? In asking this question, however, I am not after an explanation suggesting we should act with kindness, compassion, honesty, integrity and so forth. We ought to do all these things, of course, and I hope such virtues will flow from the account I shall give. But I am really after something somewhat deeper, a philosophical understanding of what it is to be a person with dementia and, consequently, how we ought to stand as human beings in relation to this person.

Aesthetics, Keats and negative capability

Well, what is aesthetics? The *Shorter Oxford English Dictionary* (SOED) gives the usual meaning, which is that aesthetics refers to the philosophy of the beautiful. Aesthetics in philosophy discusses questions such as: What is beauty? What makes something a work of art? Is there objectivity in artistic appreciation? Can works of art, music say, convey meaning (and how)? Such fascinating questions may have some relevance to the theme I am pursuing, but they are tangential. The SOED also gives the Greek root of “aesthetics” as suggesting ‘things perceptible by the senses’. Further, the SOED records that at the end of the Eighteenth Century “aesthetics” conveyed the idea of things ‘pertaining to perception by the senses’. It is this meaning that I shall use. It is not the common meaning nowadays, but I want to focus on the fundamental way in which we approach other people sensually. I want to suggest that this is what we *ought* to do: to approach people with dementia as if they were works of art even!

To epitomize this approach I shall highlight the work of the romantic poet John Keats (1795–1821). Keats was born at about the time that the SOED indicates “aesthetics” was used to mean ‘pertaining to perception by the senses’. Recall that Keats trained to be a doctor. He became a student at

Guy’s Hospital in London in 1815 and obtained his license to practise as an apothecary in 1816. By 1817, however, he was ‘throwing up the apothecary profession’ (Keats, 1990, p. 497) in favor of poetry. Only four years later, in 1821, he was to die in Rome from pulmonary tuberculosis. In that short time, however, he had written some of the greatest of the English romantic poems.

In a letter to his friend Benjamin Bailey, on 22nd November 1817, Keats exclaimed, ‘O for a life of Sensations rather than of thoughts’ (Keats, 1990, p. 365). He was clearly not against thinking, but he reveled in the sensual and the world of imagination.

‘O, let me once more rest

My soul upon that dazzling breast!

Let once again these aching arms be plac’d,

The tender gaolers of thy waist!

...

Enough! Enough! It is enough for me

To dream of thee!’ (Keats, 1990, p. 329)

Aesthetic experience for Keats was the life of sensations or intuitions. In a letter to his brother in December 1817 Keats suggested his famous notion of ‘Negative capability’, ‘... when man is capable of being in uncertainties, Mysteries, doubts, without any irritable reaching after fact & reason . . .’ (Keats, 1990, p. 370). His clearest poetic expression of this idea, albeit somewhat opaque, is said to occur at the end of the *Ode on a Grecian Urn*:

“Beauty is truth, truth beauty,” – that is all

Ye know on earth, and all ye need to know.’ (Keats, 1990, p. 289)

In September 1819, in a letter to George and Georgiana Keats, he wrote that, ‘The only means of strengthening one’s intellect is to make up one’s mind about nothing, to let the mind be a thoroughfare for all thoughts’ (Keats, 1990, p. 515). Although we only have the one example of Keats using the term ‘Negative capability’, it was a theme which dominated much of his writing. It suggests a type of openness and a lack of theory. Cornish (2011), in discussing the relevance of the idea to

social work, quotes Jackson Bate (1963) who defines three essential aspects to negative capability:

‘In our life of uncertainties, where no one system or formula can explain everything . . . what is needed is an *imaginative openness of mind* and *heightened receptivity to reality* in its full and diverse concreteness. This, however, involves *negating one’s own ego*’ (Jackson Bate, 1963, p. 208).

This characterization of negative capability led Cornish to conclude her discussion in terms which might equally apply to all those who work with older people in general and those with dementia in particular:

‘However much we are driven by underpinning ethical and theoretical frameworks on the one hand and performance demands and targets on the other, daily practice is a series of individual encounters in the ever-shifting present. Within these, open-mindedness, receptivity and humility are entirely consistent with ethically-bound, person-centered work and come together in negative capability, a richly layered concept which defines a quality valuable for service users and workers alike . . .’ (Cornish, 2011).

Elsewhere, in connection with the field of addiction, others have made a link between negative capability and narrative:

‘What might be of use for those working directly with addiction patients, in light of the mysterious and often unpredictable nature of nature, is adopting a perspective of negative capability as offered by the practice of narrative medicine’ (Hammer *et al.*, 2012).

Without making a direct link back to Keats, these authors went on to explain, ‘Negative capability is a state of mind in which an individual transcends the constraints of a closed intellectual system, such as a theory’ (Hammer *et al.*, 2012). Narrative medicine, meanwhile, through ‘literature and illness narratives’ is able ‘to build a moral imagination’ (Hammer *et al.*, 2012). Through this process of open reflection Hammer *et al.* (2012) suggest that a type of ‘sensibility’ will develop which will then inform the practitioners’ professional work. The notion of sensibility used here takes us back to the idea of aesthetics being a matter of perception by the senses. The practitioners must make themselves open and receptive to the meanings that will emerge from the narratives they encounter, which itself entails a type of humility. This is not primarily a matter of ratiocination; it is more visceral: it is how we feel things (Hughes, 2013).

The interpretation of the concept of negative capability goes further. Elsewhere, Keats wrote as

if he, as a poet, could shed his identity and thus take on the myriad of other worlds around him. According to von Pfahl (2011),

‘The complete definition of negative capability . . . implies more than passivity; rather it is the ability to do something, i.e., to assume other characteristics as a chameleon does’ (von Pfahl, 2011, p. 455).

The poet is able ‘to play many emotional roles and to create a dialog among those roles’ (von Pfahl, 2011, p. 455).

This ability stems from the receptiveness to the other, the open-mindedness, which is characteristic of negative capability. And it suggests something therapeutic, the possibility of healing that comes from engagement with the reality of others. According to the psychoanalyst W. R. Bion, negative capability is a state which ‘psychoanalysis must promote’ (López-Corvo, 2003, p. 187). Neuman (2010) adds that elsewhere, ‘Bion describes this capability in more precise terms of tolerating “empty space”’ (p. 241), which allows a direct comparison to be made with empathy, described as ‘the capability to experience the other through his existence, which is beyond our symbolic grasp’ (Neuman, 2010, p. 241). There are links to be made, therefore, between negative capability, with its emphasis on ‘open-mindedness, receptivity and humility’ (Cornish, 2011), and the therapeutic encounter based on empathy. Indeed, von Pfahl (2011) takes this further by suggesting that healing was central to the character of Keats and of his poetry. She cites Aileen Ward (1990) talking of Keats’s ‘need to be of service to others’ as being a bedrock of his character (Ward, 1990, p. 20). von Pfahl (2011) points out that as a medical student and as a nurse for his mother and brother Keats was ‘continually functioning as a healer’. ‘Therefore’, continues von Pfahl, ‘it was natural for him to think of his poetry in terms of healing’ (von Pfahl, 2011, p. 458). Negative capability plays a role here: ‘through negative capability we learn the validity of all points of view’ (von Pfahl, 2011, p. 460).

‘For Keats, the idea of poet as healer and poetry as a balm for the pain of the world was the logical next step in his creative development. Once the poet develops a sympathetic imagination, he is open to the pain of humanity – all of it; and because the poet experiences this pain first hand, to heal the pain of others is also to heal the self . . .’

Through a poetry that both pleases and heals, aesthetics and ethics become one for Keats’ (von Pfahl, 2011, p. 459).

In a letter to J.H. Reynolds from May 1818, Keats writes of the importance of knowledge in addition to sensations. For this reason, he says, he is pleased he has not given away his medical books, ‘which I shall again look over to keep alive the little I know . . .’ (Keats, 1990, p. 395). He continues:

‘An extensive knowledge is needful to thinking people – it takes away the heat and fever; and helps, by widening speculation, to ease the Burden of the Mystery: a thing I begin to understand a little . . .’ (Keats, 1990, p. 395).

The ‘Burden of the Mystery’ is a reference to *Lines Written a Few Miles above Tintern Abbey* by William Wordsworth (1770–1850). Wordsworth is talking of the influence that natural beauty has on him even much later through memory. And to these ‘forms of beauty’ he says he may have owed ‘another gift, Of aspect more sublime’. He continues:

‘ . . . that blessed mood,
In which the burthen of the mystery,
In which the heavy and the weary weight
Of all this unintelligible world
Is lightened: – that serene and blessed mood,
In which the affections gently lead us on,
Until, the breath of this corporeal frame,
And even the motion of our human blood
Almost suspended, we are laid asleep
In body, and become a living soul:
While with an eye made quiet by the power
Of harmony, and the deep power of joy,
We see into the life of things’ (Wordsworth, 2000, pp. 132–133)

In Wordsworth, too, the effects of beauty, of ‘things perceptible by the senses’, leads to a state of serenity in which we transcend our bodily selves and see the world as it really is. The aesthetic approach, that is, through openness, receptivity and self-negation, reveals the true nature of things, where truth and beauty collide into one.

Aesthetics, art and dementia

The threads that link art to dementia should already be apparent. There are, for instance, the therapeutic possibilities surrounding the idea of negative capability, whether through attentiveness to the narratives of others, or by empathic understanding, or through the ethical positioning of

oneself as open to all possibilities and the humility this requires. To return to my opening question, with its ethical spin (how do we approach people with dementia?), negative capability suggests we do so without theory, without necessarily the use of symbolic language, but perhaps with the possibility of seeing something quintessential to the person (Hughes, 2011, pp. 209–215).

The aesthetic approach, on my view, stresses perception, intuition and imagination. It is important to note that none of these precludes the possibility of scientific understanding. As Keats said, we need to widen speculation ‘to ease the Burden of the Mystery’ (Keats, 1990, p. 395). An emphasis on sense perception is basic to scientific understanding. Careful observation is a skill common to the scientist and to the artist. But sometimes intuition and imagination are also required for science to advance. Beyond a biomedical approach, however, in the psychosocial and spiritual realms, the use of intuition and imagination – for instance to understand behavior that challenges – will often be crucial. Really seeing the person, hearing her, communicating by touch, explaining something by smell, engaging in a manner that is holistic, such would constitute aspects of the aesthetic approach.

In what follows I shall, first, ask in what ways art can tell us something about the reality of dementia. Second, I shall briefly consider the possibility of aesthetic experience for the person with dementia. I shall then end by considering the person with dementia precisely in terms of aesthetic understanding.

What can art tell us about dementia?

The roots of science, after all, lie in the humanities. The human instinct to understand the world, as seen in the works of Aristotle for instance, bring together both observation and reflection. His writing specifically on artistic matters is thin – the short *Poetics* – but he conceives art as a matter of ‘imitation’ and recognizes that people enjoy seeing likenesses: the world reflected in art (Barnes, 1982, pp. 83–85). Perhaps the zenith in terms of art and science coming together is seen in the person of Leonardo da Vinci (1452–1519), of whom Gombrich wrote:

‘Whenever he came across a problem, he did not rely on authorities but tried an experiment to solve it. There was nothing in nature which did not arouse his curiosity and challenge his ingenuity’ (Gombrich, 1972, p. 222).

Careful and critical observation, however, are common not only to scientists and artists, but also to clinicians. It may be that the aesthetic approach is a way to unify the dichotomies that can bedevil intellectual discourse and, thus, provide the real holism that clinical practice requires. As we saw in Keats, understanding the world requires not just the senses but reason too; not just sensibilities and intuition, but thought also. Meanwhile, aesthetic experience is a matter of the body and the brain; it can reflect both objective and subjective elements.

So it would seem likely that through the arts we can learn something of dementia. Indeed, it may be that (as Aristotle suggested) we can learn something through imitation, by seeing likenesses. Drama is a very clear way of imitating reality and of re-presenting it to an audience. In the North East of England, the playwright Fiona Evans wrote a play, *Geordie Sinatra*, partly inspired by her family's experience of dementia with Lewy bodies (DLB). This involved her in speaking with experts on DLB, as well as conversing with people with dementia and their carers in a care home (<http://www.ncl.ac.uk/iah/news/news/item/geordie-sinatra-a-play-about-the-effects-of-dementia-with-lewy-bodies>). In turn this has led to five short films, *The Dementia Monologues*, exploring life for residents and carers in a home (<http://unitedagents.co.uk/fiona-evans>). But, of course, drama is not real life. The aesthetic approach involves highlighting elements of reality to uncover meanings, possibilities and values, which might be overlooked in the pace of everyday encounters. Kontos and Naglie (2006) discussed the practicalities and theory around the use of ethnodrama to translate and disseminate the results of ethnographic research in a manner that captures the 'experiential immediacy' that the research reveals.

Elsewhere, with artist Ashley McCormick, I have described a project that brought us together to consider the notions of memory and forgetting (Hughes and McCormick, 2003). More recently we have set out various ways in which art can induce insights into the reality of dementia (Hughes and McCormick, 2014). *Context* is important for art. The urinal that Marcel Duchamp exhibited in New York in 1917 became art by being placed in a particular setting. In dementia, the context of forgetfulness is often crucial as to whether or not it would be regarded as pathological. A malignant social psychology (Kitwood, 1997) or malignant positioning (Sabat, 2001) are both prone to make the inner pathology seem worse; whilst the reverse is also true: the psychosocial environment can enable people with dementia to live well (Nuffield Council on Bioethics, 2009, paragraph 2.39).

The *content* of a work of art is its meaning. Meanings are layered. They may result more

directly from the input of the artist; but they may also be co-created by the audience. So, too, in dementia, where the meaning of certain behaviors will need to be interpreted in a manner that involves those around. *Concern* is a natural instinct in dementia, but art shows us how the significance, for us, of things in the world reflects our standing in relation to objects and to others, suggesting the intrinsic nature of our concern or solicitude for other human beings, especially when they suffer (Hughes, 2011, pp. 47–48).

Concepts are also important in art as they are in thinking about dementia. Conceptual art suggests that the piece, in whatever medium, should convey thoughts or ideas; in fact, that these should be more striking than the material of the art (like Duchamp's urinal). In connection with dementia, therefore, art can induce or convey thoughts that challenge our preconceptions or inspire us. In our project, for instance, having looked at and discussed the various high-powered, technical means used to scan brains, and having come across the lost property box on our dementia ward, Ashley McCormick took the glasses from the box, laid them out in a tangled manner (redolent of neurofibrillary tangles) and produced a low-tech photogram, entitled *no ifs, ands, or buts*, which was then reproduced hundreds of times and distributed as a memento of the exhibition at the end of our project. Forgotten glasses, representing forgotten stories, conveyed pictorially a history, including the history of an art event, which would eventually be forgotten too.

The way in which photography might capture and represent the reality of dementia has been variously used. This recalls the French intellectual Roland Barthes writing in *Camera Lucida*:

'... in Photography I can never deny that *the thing has been there*. There is a superimposition here: of reality and of the past' (Barthes, 2000, p. 76).

Barthes grapples in *Camera Lucida* with the nature of meaning and subjectivity. He asks: 'Why mightn't there be, somehow, a new science for each object?' (Barthes, 2000, p. 8). The book was written after the death of his mother. In it, he is also grappling with grief. He searches for a photograph that captures her, but finds them all mundane until he comes across one which 'was indeed essential, it achieved for me, utopically, *the impossible science of the unique being*' (Barthes, 2000, p. 71).

Turning to photographs around dementia, the poems and photographs in Killick and Cordonnier (2000) help to capture the reality of dementia, sometimes in stark form. The accompanying poems, which were jointly composed by John Killick and people with dementia, can be wry, humorous or

challenging. In *Love, Loss and Laughter*, Cathy Greenblat (2012) set out to show, not just the sadness of dementia, but also how it is possible to live well. As in her previous work, *Alive with Alzheimer's* (Greenblat, 2004), she challenges us through her photographs to reassess our beliefs and attitudes to dementia. The aim in these works is, indeed, to capture 'the impossible science of the unique being' (Barthes, 2000, p. 71).

More startlingly, perhaps, is the work over many years of Tatsumi Orimoto. His project *Art Mama* depicts his mother, for whom he has been the main carer, over the course of her Alzheimer's dementia (<http://www.dna-galerie.de/en/artists/tatsumi-orimoto/tatsumi-orimoto-works.php>). He presents ageing and dementia in an unyielding manner, which is not however devoid of humor. Nevertheless, the intimacy depicted is sometimes unsparring. We gain a strong sense of the interaction between mother and son, but also of the lack of interaction sometimes between Orimoto's mother and those around. Life goes on. The person with dementia is lost or invisible. There is no communication with the others. But the intimate connection between son and mother is palpable, for instance in the way that you feel there is a shared sense of humor. There is an emotional closeness even in the absence of language. Perhaps this communication reflects the lack of symbolic language typical of negative capability.

There is a very clear sense in which these photographs allow us to 'see into the life of things' (Wordsworth, 2000, p. 133). What we see is sometimes disturbing or puzzling, but this is the nature of dementia. At the very least we can say that art unlocks something about dementia.

Therapeutics: aesthetic experience for people with dementia

There is little need to linger here, for it is clear to all those who work with people with dementia that a variety of artistic approaches can enhance quality of life. There are three caveats to this statement. First, it is sadly too common that people with dementia live without meaningful activity, so that any form of entertainment or creative pursuit is greeted with pleasure and enthusiasm. Given the low base-line, aesthetic pursuits are bound to improve quality of life. Second, it cannot be presumed that people will enjoy a particular artistic activity. Not everyone likes popular music, even from the 1950s! There can be mixed reactions. Third, it is almost inevitable that research is generally not of a high enough methodological rigor to provide a good evidence base to encourage the use of artistic interventions in

dementia care. A systematic review of art therapies and dementia care concluded that there were a number of methodological gaps (Beard, 2011). The review also opined:

'Models investigating subjective well-being, or 'enrichment,' rather than objectively measured biomedical approaches privileging the management of deficits, would expand the evidence base and help ensure that those with dementia receive the services they want, since strictly allopathic methodologies will continue to fall short of adequately evaluating what are deeply idiosyncratic psychosocial issues' (Beard, 2011).

The range of creative artistic work involving people with dementia is impressive, from music to visual arts, from drama to dance-movement therapies (Beard, 2011). Each of these arts has used different approaches, so the field is extensive, but this poses problems when it comes to comparing studies. A Cochrane review of music therapy demonstrates the extent of the problem with methodology (Vink *et al.*, 2003): there were 354 references to music therapy and dementia, but only 100 were research studies, of which only 10 were considered in the study. The review found that 'The methodological quality and the reporting of the included studies were too poor to draw any useful conclusions' (Vink *et al.*, 2003).

Having said this, my personal experience in a unit for people with advanced dementia is that, when professional musicians come to perform, some people who had great difficulty with communication and engagement were noted to be tapping their fingers to the music. The general feeling, even if one or two people objected, was that people enjoyed the experience. We are inevitably dealing with subjective experience and 'deeply idiosyncratic psychosocial issues' (Beard, 2011). This also suggests that a great variety of aesthetic approaches might be of value (cf. Hughes, 2011, pp. 241–246).

For example, Wallace *et al.* (2013) showed how co-creation of both jewellery and digital jewellery, involving the person with dementia and her spouse in co-operation with the jewellery-maker, supported by a team with interactive computer design skills, could support personhood through both a sense of agency and by reminiscence. But the designs were intensely personal, drawing on detailed narrative accounts. The idiosyncratic, the importance of communication and interaction, all of these are characteristic of an aesthetic approach.

The Person with Dementia: an aesthetic being

If the design of jewellery supports personhood, this is because there is an inherent connection between the aesthetic approach and our sense of being a

person. But this has not always seemed apparent. John Locke (1632–1704), the English philosopher, described the person thus:

‘... a thinking intelligent being, that has reason and reflection, and can consider itself as itself, the same thinking thing, in different times and places; which it does only by that consciousness which is inseparable from thinking, and ... essential to it’ (Locke, 1964, p. 211[II. xxvii. 9]).

It was not Locke’s intention, but this view poses a direct threat to the claim that people with dementia are persons (Hughes, 2001). Some have doubted that people with severe dementia should be designated persons at all (Brock, 1988). The contemporary philosopher, Derek Parfit (1984), has defined personal identity in terms of ‘psychological connectedness’ and ‘psychological continuity’. If I cannot connect my psychological states into a continuous chain, he would argue, I lose my identity as a person. (I am not doing full justice to these arguments here, but see Hughes, 2011, pp. 34–54.)

Now one immediate thing to be said as a retort to this view is that it is evidence of what Stephen Post (1995) has described as our ‘hypercognitive’ society. He detected ‘a persistent bias against the deeply forgetful’ (Post 2006, p. 231). This hypercognitivism lauds memory and downplays other aspects of our personhood, such as our relationships and emotions. It is the basis of stigma. Elsewhere, Post has commended a new form of hospice for people with dementia.

‘Efforts to enhance emotional, relational, and esthetic well-being would, under such a plan, be enhanced in ways that involve family members, providing them with a sense of meaning and purpose. Through music, movement therapy, relaxation and touch, such efforts support patients’ remaining capacities. Connections with nature through a beautiful and open environment fit under this rubric, as can spiritual support’ (Post, 2000, p. 107).

This vision is based on a much broader account of what it is to be a person. I have characterized this as the situated-embodied-agent (SEA) view of personhood (Hughes, 2001, 2011). I shall not repeat the details of this view here. The key notion, however, is that we are situated in multifarious dimensions of culture, personal history, social context, as well as moral and spiritual fields. Part of our embodiment means that we engage with these dimensions of our world through our senses, as well as by our understanding. Our world is, after all, a physical one, but it is also constituted by moral, political, cultural values and so on. In addition, our appreciation of the world includes a sense of what

is beautiful and what is not. Part of what it is for us to be the persons that we are is that we have this aesthetic sense. As the philosopher Merleau-Ponty (1908–1961) wrote in the Preface to his major work *Phenomenology of Perception*: ‘The world is not what I think, but what I live through’ (Merleau-Ponty, 1962, p. xviii).

We live through the world by our senses. We are inherently aesthetic creatures. The SEA view of personhood makes the point by presenting us with a broad view of what constitutes us as human beings of this type. Keats’s negative capability is a plea that we should stay open and receptive to this broad, aesthetic sense of the world. The ‘human person perspective’, the broad view, demands that for human beings nothing is ruled out (Hughes, 2011, pp. 226–228; 236–237; 241–249). Our understanding, therefore, of people with dementia must be broadly based (Hughes and Beatty, 2013). Our approach to people with dementia should be an aesthetic one, with openness, receptivity and humility.

Conclusion

In his book on romanticism, Isaiah Berlin concluded that we owed romanticism a great deal.

‘We owe to romanticism the notion of the freedom of the artist, and the fact that neither he nor human beings in general can be explained by over-simplified views such as were prevalent in the eighteenth century and such as are still enunciated by over-rational and over-scientific analysts either of human beings or groups... The notion that there are many values, and that they are incompatible; the whole notion of plurality, of inexhaustibility, of the imperfection of all human answers and arrangements; the notion that no single answer which claims to be perfect and true, whether in art or in life, can in principle be perfect or true – all this we owe to the romantics’ (Berlin, 2000, p. 146).

Aesthetics, as that which pertains to perception by the senses, is a notion that does not detract from rational and critical thought, but it sets our rational being in the wider context of competing values and varied cultures. So an open-mindedness, a receptivity and degree of humility are required as we struggle to understand the world, the burden of the mystery, the life of the person with dementia. We shall not only learn about them by their brain functioning, we shall also learn about them by observing closely their gestures, their actions and their interactions. Our intuitions may be uncertain. But our approach must be aesthetic, so that we hear what they say and see what they do ‘without any

irritable reaching after fact & reason' (Keats, 1990, p. 370).

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