

Dementia is under scrutiny: 850,000 people in the UK are living with the illness, and one in three people aged over 65 will have dementia by the time they die.<sup>1</sup> This is predicted to rise to over two million by 2051. There is an urgent socio-political call for action,<sup>2</sup> driving up research into causes and for a cure, looking towards prevention, improving treatment and raising care standards.<sup>1</sup>

As a feminist and dance movement psychotherapist with a background in choreography and filmmaking, my response to this socio-political call is to turn my lens to the collaborative and embodied experience of dementia: the dynamic confluence of the psychological, social and biological across our lifespan. Informed by my own clinical practice in the NHS with older adults living with dementia, as well as my experience of creating artistic work for the purposes of social intervention, I collaborated with composer Jill Halstead in a piece of internationally funded arts-based research, including the short film *I Can't Find Myself*.

People's voices and lived experiences are at the heart of *I Can't Find Myself*. I developed the choreography and Jill created the sound score for the film and these elements are based on our collaborative fieldwork and verbatim interviews undertaken with people who live with dementia and with their carers, from a variety of cultural backgrounds. These voices speak of the urgent psychosocial requirement to improve wellbeing and enhance the quality of everyday relationships for people living with dementia. Every time we screen *I Can't Find Myself* we call out to all those family members as well as clinical and care staff, who act as extended 'family', in order to explore

collaborative and creative solutions. To this end, throughout 2015–16, we are distributing the film via the project team partners (Dementia Pathfinders, the University of Roehampton Department of Psychology and the Grieg Academy of Music at the University of Bergen) for education and training purposes. We want it to be seen by people employed in services that are concerned with people living with dementia, such as care home and domiciliary care staff, mental health nurses and doctors, emergency services and hospital A&E staff. Our aim is for the film to act as a reflexive social tool in order to develop support and understanding, improve the quality of relationships and raise care standards in a creatively conscious way.

### A rich journey of the senses

I am interested in finding ways in which counsellors and psychotherapists can creatively engage with people experiencing dementia. How can we reach both lay and professional carers in order to enhance and sustain empathic and intimate relational engagement and understanding of how to communicate with, and care for, those living with dementia? To explore some embodied possibilities in therapy practice, I invited a professional dementia educator and carer, a psychotherapist and a counsellor to respond to the film. Their comments are included below. My own response to each of the three professional voices aims to highlight embodied awareness and understanding of how to engage with and re-build the often fractured intimacy of relationships with self and others that can occur with the onset and development of dementia.

Specifically, our aim for the film is to create a wider understanding of people

living with dementia and to highlight how engagement with the entangled relationship between dance and music can enhance *affective and kinaesthetic* responses – not only for those who live with dementia but also, crucially, for their network of carers.

The recent turn towards re-defining 'affect' describes it as a process of embodied meaning making.<sup>3</sup> A crucial aspect of embodied meaning making involves how we quite literally 'make sense'. Kinesthesia can be defined as 'the sense of movement' and is informed by all the senses, as well as internal sensations of muscle tension and body position. Also, we know, through research in the fields of cultural studies and neuroscience, that all the senses interrelate.<sup>4</sup> Here Julia Burton-Jones, a professional dementia educator and carer who works for the social enterprise Dementia Pathfinders ([www.dementia-pathfinders.org](http://www.dementia-pathfinders.org)), reflects on her kinaesthetic response when watching the film and how the moving body can be seen as a vehicle for kinaesthetically-mediated empathic responses.

*'For people with dementia, it can be difficult to put into words the feelings and experiences they face in living day-to-day with the uncertainty and confusion caused by the condition. I Can't Find Myself takes us on a rich journey of the senses and leaves a profound impression on the audience, conveying the truth that dementia touches us in body, soul and spirit, and not just in mind. The film packs an emotional punch: it does not hide the pain and distress that can be caused, but offers hope in showing glimpses of the warmth and connection that remain...'*

*'[W]hether they are a person living with dementia, supporting a relative or friend,*

# Dementia and embodied psychotherapy

*Beatrice Allegranti* has created a short film to help clinicians and professional and family carers develop their understanding of the experience of people with dementia and support them creatively



or someone concerned, [the film] could be used as a staff development tool but also as a vehicle for allowing people with dementia and their families to open up about their feelings and the impact of the condition on their relationships.'

I am struck by Julia's affect-laden words: 'The film packs an emotional punch.'

Dementia is a visceral and inexplicable experience and the relationship between language and the body is both changed and challenged – for the person living with dementia and for everyone around them. As I write this I am transported to the private and public screenings and subsequent discussions of the film within a variety of professional contexts where I kept hearing the words: 'I didn't know what to expect' and 'I didn't expect to be so moved.' These realisations throw into relief a parallel process: the audience's affective engagement when witnessing the film, as well as their lived personal and professional experience of dementia relationships. There is kinaesthetic intimacy in watching the film: it activates our senses<sup>5</sup> and directs our attention through camera angles, proximity, colour, sound, igniting our own personal embodied responses, sensations and memories in ways that may invite us to see and feel 'otherwise'.

Often, the focus on understanding dementia, providing treatment and engaging in communication can emphasise verbal interaction, and the value of non-verbal communication can be ignored. As Julia states, continued connection is important, and, as such, attention to kinaesthetic engagement is key – not only when people's cognitive faculties are impaired but more so within/in dementia relationships where

meaning making through language as we 'know it' is changed and challenged.

We cannot escape embodied entanglements in life or in psychotherapy. Changes in physicality or gesture influence affective state, and the implications for this are profound. As people move together they learn different ways of relating; they develop shared networks of meaning making and communication that are important to intersubjective relating, neurologically and psychodynamically.<sup>6</sup> Both dance movement psychotherapy and neuroscientific research highlight how our ability to feel with others is intimately connected with our capacity to move with others, and for our bodies in turn to move in response to such feelings.<sup>7,8</sup> Moving with others, as Julia says, *touches*.

The intimate dances that unfold in the therapy relationship also mean working with difficult, often taboo feelings around loss – *the emotional punch*. In the context of dementia, loss is acutely present for the person living with the experience, as well as for family and carers who are witnessing the change. After one private screening and feedback session, a member of the audience became angry that the film evoked a sense of loss, and targeted their anger towards me. As I travelled back on the underground, head in my notebook, trying to stifle my tears on a crowded rush hour train, I was aware that these were old tears, relating to my own resonating experience of care, nurturance, love and loss. What sense can we, the family and the professional carers, make of being in a place where we can no longer recall significant memories in our lifespan and the people associated with them? For the person living with dementia, as for all

of us, developmental memory is embedded; we bear the imprint of our bodily experiences over time. So how can the family and extended family of carers and therapists work towards a safe and fulfilling holding of these new identity shifts? How is it possible to hold the tension of witnessing a loved one's simultaneous presence and absence?

### Remembering and finding

Who am 'I' without the other? Amidst the personal and public picture of isolation, stigma and lack of understanding about dementia, there is a vital campaign for person-centred care that emphasises the lived experience of people with dementia and their relationships.<sup>9,10</sup> Emphasising personhood means understanding that the person living with dementia undergoes neural, cognitive and affective change and that this change is a distributed and dynamic embodied process.<sup>11</sup> Also crucial to an understanding of selfhood in psychotherapy is acknowledgement of the relational process – all the more significant in the context of dementia where a network of individuals can be seen to be creating embodied meaning together.

Collaborative meaning making is, of course, an intersubjective process: one of mutual recognition where we can shift between being in relationship as well as observing relationships around us. In the dementia relationship, as with any traumatic experiences, the capacity to observe breaks down. Therefore, as therapists and carers, the intersubjective question we may find ourselves asking is, 'How can I remember for the person living with dementia?'

The second response to *I Can't Find Myself* is from Marina Rova, a dance

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movement psychotherapist based at East London NHS Foundation Trust, who has worked on an NHS continuing care dementia unit. Marina describes her own embodied resonance as a starting point for intersubjective relating:

*‘This short multi-layered film speaks, sings and dances the lived experience of dementia. If, as witnesses, we become baffled in trying to solve the puzzle of the, at times, peculiar and other-worldly narrative (and imagery) of I Can’t Find Myself, it is because we are not looking, feeling or listening hard enough. Because dementia is peculiar, other-worldly and alienating. Most importantly, the film highlights that dementia is unavoidably an embodied, relational and affective experience.*

*‘As a clinician (and researcher) I am particularly interested in continuously developing relational and embodied approaches in supporting those who live with dementia and their carers. Watching I Can’t Find Myself brought back stories of the people (and their family members) I have worked with. Whole lifetimes captured in the fleeting moments of connection, companionship, seeing, bearing (the pain) together: a breath, a touch, the intimacy of sharing the unspoken. I Can’t Find Myself reminded me that attending to what I can know (with) in my own (relational) body helps me understand what the other may be experiencing in theirs. When all that is lost for the person living with dementia leaves a gaping numbness and disorientation, what remains becomes a possibility, a bridge we can both walk and meet halfway to find each other. And if you (the person living with dementia) can only manage a few steps, I (the carer, the family member, the clinician) can walk the extra steps for both of us. And maybe if I can see you through the veil of distortion and isolation*

*that dementia skilfully weaves between us, then you may be able to see yourself for a moment. If I can find you, I may be able to help you find yourself.*

*‘I Can’t Find Myself communicates all that is unspoken in the lived experience of dementia. It calls for our attention (and intention) in our relational and kinaesthetic engagement with people living with the illness. It is not about what we can do for people living with dementia; it is about how we can be with them.’*

When I read Marina’s words I immediately hear Judith Butler’s voice:<sup>12</sup> ‘The boundary of who I am is the boundary of the body, but the boundary of the body never fully belongs to me.’ What is afforded to us, as therapists, as carers, I wonder, if we begin to understand in our intersubjective engagements that we do not inhabit ourselves by ourselves? Our sense of self emerges from our developmental relationships; we learn to understand not from conceptual knowledge but through intersubjective bodily interactions and feelings during an early intimate dance with our primary caregiver. A common experience for the person living with dementia is losing a sense of self – what, then, of their experience of loss, vulnerability, intimacy and dependence?

We can support those living with dementia to learn to move themselves into life after loss. As Marina reminds us, perhaps as witnesses ‘we are not looking, feeling or listening hard enough’. Embodied interventions suggest that movement, emotions, cognitions and the body are not separate – they are entangled. A kinaesthetic awareness when engaging with a person living with dementia can allow for a relational

intimacy – however fleeting (to borrow Marina’s words) such moments of connection, companionship, seeing and bearing (the pain) together may be. Biologist Ann Fausto-Sterling<sup>13</sup> points out that our bodily self-perception is formed on the basis of past information, which by definition is always out of date with our current physical body. So, embodied attention during the psychotherapeutic relationship with people who live with dementia offers a crucial possibility to activate the mirror neuron system in the brain, thus linking bodily awareness, empathy and intersubjective processes.<sup>14</sup> We can invite the person with dementia to re-member through the body. In my role as both clinician and educator I have observed over the years how the materiality of movement exchange between self and other can allow for an experience of finding self in other. For the dementia family this can mean re-connecting and building new kinds of relational intimacies with a loved one; for professional carers it can mean re-learning about a relational intimacy.

### **Summoned**

Bearing witness to dementia and holding an embodied awareness in dementia relationships is a political call – we are summoned both personally and professionally. In this last reflection on the film, Jonathan Wyatt, Director of Counselling and Psychotherapy at the School of Health in Social Science, University of Edinburgh, speaks of this kinaesthetic and affective call:

*‘You hear the guitar’s summons, sense the soft/hard touch of fingers on taut nylon, the crystal moment of a note, then another, and another, together. You hear voices.*

**‘When all that is lost for the person living with dementia leaves a gaping numbness and disorientation, what remains becomes a possibility, a bridge we can both walk and meet halfway to find each other’**

*Her song; a call, a break in the air, words that reach you, reach in, hands stretched to find you, to take you. You hear his, her voice, others' voices, spoken, soft, harsh, lost, loved, loving. Sad. Hopeful. And you see, too, of course; you see, you watch. You watch stories, broken. Fragments of living, like dreams. Across the screen, back and forth, here, there. Flows of touch and holding, knowing and unknowing; recognition gained then – snap – strange. Estranged. All. Nightmares of the lost and found and lost.*

*'You see, hear, watch, feel, bodies. The way bodies make contact; embracing, falling, rolling. Gestures that convey memories. Memories and their exquisite, fleeting joy; and their loss. Loss that only others can mourn. He shows her the movement of a hand, the way it shapes an invitation; you see her see, you see her know, you see her raise her hand, you see her make that same, that very same gesture; you see her emerge, for a moment, a moment, the joy, then – snap – lost. Loss. His. You watch bodies embrace, you watch skin against earth, earth on clothing, earth on skin, daubed, a covering. A recovering.*

*'You pause when it ends. You sit. You look out of your half-window and its dull, half-light on Tuesday's late summer evening. You touch the skin on your cheek, feel its roughness; you try to take breath, try to feel the breath from further down, but it's difficult. You have with you the sense of the man you will see, who will sit with you here for the nearly-hour, in this room. You and he together. The man who is losing. The man who is losing her, the one he can no longer find. You think about them, their embraces, their touches; their fleeting, momentary contact, which he cherishes and longs for and is losing. And you wonder if you, perhaps, between*

*you, can shape mirrored gestures even if they are but there then and – snap – gone.'*

A range of vulnerabilities is present in the experience of loss. Loss evokes the disruption of *ipseity* – the feeling of identity, corporeality, existential orientation and being the perspectival origin of one's own experience – all these are basic components of the experienced differentiation of self from non-self.<sup>15</sup> And yet gestures and memories, embodied attention in the counselling and psychotherapy relationship, can be a way of reminding us to remain open to the possibilities through which bodies make sense; new kinaesthetic memories can be created.

A sense of loss and disorientation is not uncommon in psychotic experiences generally and is a common feature of the advanced stages of dementia. This sense of loss exists in a tangled web of self–other relationships.<sup>16</sup> What happens when, inside the therapy room, we bear witness to a life's unravelling? A body's unraveling (*snap – lost*)? Loss of tangles and plaques – the ruthless biological process that biomedical science is labouring to impede.

What is it to step into the other's world when they have lost their moorings? How can we be with this in our own bodies as counsellors and psychotherapists? Confronted by loss, carers and therapists can experience strong embodied counter/transference feelings for the person with dementia. Butler is aware of this incorporation too: 'I think I have lost "you" only to discover that "I" have gone missing as well.'<sup>17</sup> How does the body of the other summon us to engage? It is the embodied relational engagement that sustains us in the living of everyday life. And, as Jonathan's

words vividly attest, relationships are made up of *gesture, voices, spoken, soft, harsh, touch, skin, breath, embrace.*

An individual's embodied loss is entangled within the wider social context of care. Addressing the multilayered aspects of loss inside the therapy room can have reverberations in the wider socio-political context. Perhaps we can address our cultural relationship with loss, aging, illness and death in a way that helps us to enter into new types of relationships, free from fears about differences between self and other and with the respect and courage to learn from the person living with dementia. Dementia is part of everyday life – we are all summoned to this reality of loving, losing and living. ■

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*I Can't Find Myself (directed by Beatrice Allegranti, 2015, 12 minutes) was premiered at the Olympic Studios Cinema, London on 9 May 2015 and has subsequently been screened across the UK and Europe. Forthcoming screenings and accompanying short seminars will be at Hampton Hill Theatre, London on Wednesday 16 March 2016, in partnership with Dementia Pathfinders and St George's NHS Trust, and Friday 10 June 2016, as part of the Embodying Social Justice Conference at the University of Roehampton. For booking details and updates, please see [www.beatriceallegranti.com/news](http://www.beatriceallegranti.com/news)*

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