**Conversations in Social Justice:**



Dementia, Personhood and Social Justice – the Role of Creativity

Series 1. Episode 7

*Dr Helen Pleasance and Caleb Klaces, both writers and Senior Lecturers at the York Centre for Writing, York St John University, speak to Dr Lucy Burke of Manchester Metropolitan University about the role of creative writing in achieving social justice for people with dementia. They discuss the concept of ‘personhood’, the ethics of literary representations of dementia and Lucy’s recent activism in response to the UK government’s COVID-19 policies.*

**Helen Pleasance**

Welcome to the latest conversation in social justice, the Institute for Social Justice’s podcast series. I'm Helen Pleasance, Senior Lecturer in Creative Writing at York St. John University and in this podcast my colleague, Caleb Klaces, also a Senior Lecturer in Creative Writing, and I will be in conversation with Dr. Lucy Burke, who's a principal lecturer in the Department of English at Manchester Metropolitan University. Lucy’s research focuses both on how dementia is represented across literature, autobiography, and film and television texts, and on how we might think about the role of the arts and humanities in relation to the lived experiences of dementia. In exploring creative approaches to social justice for people with dementia, we will talk about both these areas of Lucy's research with her today. My own interest in dementia and how creative practice might contribute to our understanding of and engagement with it has various sources. Firstly, and as with a lot of people my closest contact with dementia is through a family member, in my case, my mum who had dementia, and it was particularly her enforced isolation from my brother and me in a care home during lockdown last year that highlighted for me the precarity of anybody with dementia in relation to social justice. But then secondly, as a creative nonfiction writer and teacher, I'm very concerned with how writers write about people with dementia. I am writing about my mum at the moment. And it's something that I'm very preoccupied with the issues involved in this, including the ethical ones. And then on my undergraduate creative nonfiction module, I've been struck by how many students write really movingly about their relationships with relatives, mainly grandparents, with dementia.

I've been aware of your research for a long time now, Lucy, because over 10 years ago, you were my PhD supervisor. And while my PhD wasn't about dementia, it was about memoir and its potential to radically undermine other truth telling forms, so the sub-genre of the dementia memoir is something I'd definitely like to discuss further with you today, among many other things. Firstly, I'll hand over to Caleb though, who was the instigating force behind inviting you to the podcast to say a little about why he wanted to do so.

**Caleb Klaces**

So I discovered Lucy's work a bit more recently, and it was kind of in the teeth of a very difficult period for my dad. And over the last year or so he's kind of become unable to look after himself and has recently moved into a care home. And one of the things that I noticed about this process was the way his profound sense of dislocation, of not having a place in the world seemed to be reinforced, or at least initially, by the care system, and by the construction of dementia in the literature that I gravitated towards, to make sense of kiwhat was happening. On the other hand, I also don't quite trust my own impulse as a writer to sort of launch a rescue and recovery mission with the written word. So, what I found incredibly helpful and refreshing about your work, Lucy, is the ways it rigorously and sensitively and often ambivalently explores the connections between these things - intersubjective lived experience, the care system and creative representations, always emphasising a sense of their contingency, and the possibilities for change. So I'm very grateful to you for talking to us at what I know, is a really busy time. So my first question has sort of two parts. What drew you to researching dementia? And how would you explain or describe what it is that you are researching when you are researching dementia?

**Lucy Burke**

That's a really good question and a difficult question. The second part particularly, but I became really interested in dementia on the back of reading and watching, actually, a film poem by Tony Harrison, *Black Daisies for the Bride*, which I was initially drawn to because I was really interested in the way that Tony Harrison writes about class and gender. And that's why I sort of wound up watching this and then I was at the same time as I was interested in writing about *Black Daisies for the Bride*, which is about a group of women who are in hospital at what was one of the big kind of Victorian asylums type mental hospital in Leeds called High Roads. It was about a group of women there and towards the end of their life and the film actually filmed these women and the poem kind of constructed an idea of what it is to live with dementia, but really articulated around the idea of marriage so it kind of revisits the moments of their own marriages and then also imagines them married to Alzheimer’s, and sort of really postulates the sort of role of art and poetry in a sort of salvage operation for those experiences, but in a way that I find quite problematic, actually. And I can talk a bit about that in a minute.

But at the same time, as I was trying to find ways of writing about this film poem, my grandmother was really dying, and she had a vascular dementia. And she was somebody who'd grown up in this incredibly strict Salvation Army type background, right, and spent a life really constrained, you know, my mum was forced to sign the pledge when she was very little, and my grandma was quite a sort of buttoned up sort of person. And suddenly, towards the end of her life, she was swearing like you’ve no idea. And it was all coming out and a lot of fury and a lot of anger and a lot of despair and it really struck, going to see her, about the ways in which different members of the family were making sense of what my grandma was doing. And the lenses through which what she was doing and how she was behaving, were explained. So, I was aware that I was drawn to this, I would guess, a kind of psychoanalytical framework of sort of thinking about what was being exposed by the way she was behaving and a sort of story-based way of understanding something about her life, something about what had happened to her, something about what was happening now. Whereas other members of my family were absolutely sort of were saying things like, well, this part of her brain is not working anymore. And it's really a kind of medical way of thinking about it. Now, alongside that as well, my son, who was 20 months at the time, lost all of his language. And, you know, over the course of a year was diagnosed as autistic. And I was watching him engage with the world in a really different way. And I was confronting and encountering a kind of real sense of difference, his difference, a kind of cognitive difference.

And all of these things were sort of going on in my head. So, I was thinking, okay, so how is it we know the things we know about ourselves and other people, about forms of cognitive impairment and cognitive difference? What frameworks do we have to make sense of those? How do those kind of shape particular ways of feeling and responding to all of these experiences and so that's really how I became interested in thinking about dementia. And I think I spent a long time trying to understand and connect the different kinds of frameworks that people use to understand these things. And to understand the impact of social environmental, sort of systemic factors, like, you know, how do we organise care, and how does the way we organise care have a bearing on how we understand this difference, and have a bearing on the lived experience of it. And so, I was drawn to try and sort of work all these through sort of, via a combination of a kind of a critical interest in writing and representation and the ethics of portraying particular groups of people, and something born out of my own experience and my own desire to find new ways of thinking about things. In other words, a resistance to the ways in which we are perhaps encouraged to understand dementia and disability through a kind of deficit-led framework.

**Helen Pleasance**

What you've just said, this seems like a really beautiful description of kind of interconnectivity or intersubjectivity. You know, here's kind of like, here's you, looking at your gran, looking at your family members looking at your gran and, you know, telling stories about what your gran's behaviour means. And then there's you and your son, and you thinking about what his behaviour means and how other people interpret his behaviour and how he's interpreting the world. And so I just thought that you've done is really just demonstrate something I think is at the centre of your research, which is this concept of personhood, and how we think about what a person is, and I just thought it would be useful, illuminating, to say a bit more about why personhood is so important to how we think about, not just dementia, but everybody and what kind of concept of personhood that would be.

**Lucy Burke**

Yeah, I mean, personhood is a kind of critical concept in a lot of bioethical work. It's an idea that is subject to debate. And you're right, it is central to a lot of things I write about, but there are significant implications for anybody thinking about sort of the rights, the identity, what it means to live with dementia in relationship to the kinds of models that we use to understand it. So, at the beginning of the 20th century, dementia was something that happens to people when they were older, and it was just a kind of assumed characteristic of ageing. In other words, when people get old, they become forgetful, and so on. Now, what happens over the course of the 20th century is for all kinds of reasons and to do with all sorts of pressures, you kind of have the emergence of a biomedical idea of what dementia is. So, it becomes a kind of disease category. There are advantages to that, because when something becomes a disease category that can be measured and looked at in particular ways, you can imagine and invest in the possibility of a cure. Although the cure for this thing we call dementia, it's always around the corner, it's always just about to be developed, you know, there's always a promise of it, but it's never yet kind of appeared. But the biomedicalization of dementia and understanding in that way can give rise to very hyper cognitive sort of ideas of the self which are linked to the brain. So, what goes hand in hand with the biomedicalization of dementia is this kind of sense that brain and brain function is the locus of mind and self, you know, which is a really different idea to a kind of psychoanalytical idea, which is that language and the passage of time and events and trauma and these kinds of things are the locus of how we might understand self. So, you get a kind of flattening out of, you know, ideas of what constitutes us as people. And so, you have people who believe that kind of personhood is something which is connected to cognitive function in lots of ways. And therefore, would view people living with dementia as potentially not having this thing called personhood, because their brains aren't working in the same way.

Now you have other people -this is something called the personhood movement in dementia studies - who argue very strongly that you shouldn't reduce the self or personhood to cognitive function, and that it's important to recognise that personhood exists and persists regardless. And one of the things that is crucial there is understanding that what makes a person and what constitutes how we might understand ourselves in the world is via a set of relationships, and relationships with other people. And that even if someone is unable to tell their own story, that people around them can still be part of that sort of meaning making process. And there's lots of evidence that, you know, people with very severe dementia continue to express themselves in various ways, even, for instance, interestingly, through things like music or other ways of responding can still sort of express self in the world, even at the very end of their life. And so, there are different ideas of personhood, I guess, for me, as a matter of principle, I gravitate towards the kind of extension of personhood, but I do think that there are sort of difficulties with that as well, and there are difficulties with it that are tied to its reliance on ideas of intersubjectivity. Because, of course, everybody's identity, and everybody around a person with dementia may have their own identity kind of thrown into crisis. And it might be difficult, you know, the act of sustaining personhood is not a given. It's a challenge. There's a kind of ethical prescription, it's like a desire to do it. I think in practice, it is, you know, it's not without its problems, or its kind of challenges for the people around that person. So yeah, that's how I sort of think about personhood in my work. But I'm also really interested in thinking about personhood, outside of ideas of narrative as well, of displacing the centrality of narrative to the ways in which we might think about how we may express self in the world, to think about interactions in the present, or the ways in which actually people can be themselves through ways of interacting, which have nothing to do with narrative and have everything to do with maybe sort of sensory experiences. I've read dementia memoirs, where people talk about the sort of feeling of a flower, or the exchange of a set of glances or of laughter in the moment, which is a very different way of understanding how we might think about ourselves.

**Caleb Klaces**

There's so much to pick up on there. I was just going to ask you about the kind of relationship between ideas of personhood and narrative and how kind of deep that seems to go and how other forms of experience which you might call lyric that are kind of maybe fragmentary, or kind of happening in the present might be a sort of alternative to that. And I think that really links to a question, which seems to recur in your work, which is about sort of who the writing might be for, if somebody is writing such things. Is it as a sort of an attempt to represent a particular experience which is just maybe beyond the horizon of the known or even perhaps the knowable, or is it actually something that might be more collaborative? And I think there are different modes that you explore in your work. And I wondered maybe if you could talk about that.

**Lucy Burke**

There's a lot in that question. I read a French writer called Annie Ernaux’s accounts of her mother, and her mother's kind of experiences with dementia. And I read those, and they're generally quite well thought about, but I felt very uncomfortable about the ways in which some of that was depicted, because in some senses, it felt like, there's the potential for a kind of representational violence to someone who can't either consent to their representation or challenge it. So I was really aware of that in that kind of writing, and what it means to do that, and what it means to represent another person, and at the same time, what it means not to represent another person, because I think it's very important that these experiences are brought to life, and people aren't hidden. Because, you know, a lot of people who live with dementia, you know, experience what some writers have called the kind of biosocial deaths, it's almost the idea that you're kind of in this Limbo between the world of the living, and death, and you are sort of physically separate. And you know, in the sense that you may be in a residential care, and that your experiences and never shown and so and that kind of reinforces ideas of the kind of horror connected to dementia rather than I suppose it's, you know, the fact that in lots of ways, it's not an extraordinary experience, it's an ordinary experience for so many people. I use ‘ordinary’ not to sort of diminish it, but to say, this is something that isn't unusual, and that the more that we could understand it and explain it, perhaps we might be able to think about it differently as well. So there are all these kinds of problems about sort of, you know, who represents and how and to enable that, and I suppose, you know, I've also worked with people with dementia in residential sort of care settings. So, I was part of – not a major part of - the project that took *The Tempest* as a kind of play text and worked with people to produce a sort of co-produced version of it. And what was interesting in that was the extent to which the participants, many of whom had what you might describe as, you know, were living with significant issues in relationship to their dementia and into the memory and all sorts of things, how they expressed themselves through that process in really interesting ways and how people's personalities came through in the process.

**Caleb Klaces**

As you were talking, I was thinking about the kind of thing, like sometimes, the fear is over kind of disorganisation of the normal, that sort of comes from this space of dementia, rather than a fear of what's unknown, you know, it's almost like that it might be dangerous to actually understand it in some way or represent it in some way.

**Lucy Burke**

You know, dementia has become this kind of massive condition that people most fear. And it overtakes sort of in the early sort of 2000s, it overtakes cancer as the condition that people most fear. And this isn't surprising, because it's described as the condition people should most fear. And in a culture, which is really sort of predicated on death denial, and the idea of dying as a kind of obscenity, then dementia becomes the space where all of those fears, I think, are condensed, because it's the one way of dying that we can't imagine there's a solution to. Even though people die of cancer, there's still an idea that this can be overcome or cured, or you can battle again. You don't have any of those resources in relationship to dementia. And that's why I think people find it so difficult. And why it then becomes also, in part becomes, this thing that people try and sort of contain within a certain kind of framework. Or it happens over there to these people we don't see. I think, you know, from the work that I did, and the people I encountered, you see people living really well. And you see moments of great joy and humour and fantastic disruptiveness. When we were doing the work in the residential care home, I went to one session, and they were talking about sort of Stephano and Trinculo in *The Tempest*. And one of the women who was doing it, she was just everything somebody said, she would say to you just say, and she would say something really rude, which I won't say on this podcast, but like, ‘Did you just say *this* *thing*?’ And it was actually so funny, because it was completely attuned to what we were talking about, you know, to the kind of carnivalesque elements of *The Tempest* as well, but kind of all of this joy in this person. The fact she had dementia wasn't making any difference to that, it was really kind of coming through. I think, and obviously people have different experiences and more difficult experiences, but you know, there isn't one way of living this, and it isn't a single thing. And like every single interaction and experience we have in life, there are funny moments and bad moments, but they're not eradicated by a diagnosis. And I think that's what people often don't allow themselves to think about particular conditions, you know, you reduce. The kind of dominant sort of tendency seems to be to reduce people to a diagnosis, and to explain everything via that rather than sort of still maintaining that sense of people as being diverse - life as being diverse will have sort of different kinds of moments of being possibilities of laughter and connectivity, as well as sort of pain and loss.

**Caleb Klaces**

You know, one of the things that really strikes me, it's also about the degree of change, that's admissible in a narratable identity. So is dementia, such a radical threshold, that it transcends any of the other kinds of change that might happen over a lifetime, the change between childhood and adulthood, for example, or from being a baby to a kind of toddler or those sorts of things? And it may be that there is sort of something that is more radical and different and challenging. But I think part of what's challenging about it is because it makes us think about identity as something that may be very discontinuous over a lifetime.

**Lucy Burke**

I think a lot of people who really embrace this sort of hypercognitive brain type idea of dementia, people like Catherine Malabou, who writes about, you know, neuroplasticity, and sort of destruction, for them dementia is this kind of absolute break, and produces a kind of radical alterity and a real rupture. I'm not someone who is sort of hostile to neuroscience, or to the ideas that, you know, there is a relationship between what happens in the brain and then how people experience themselves, but I think it's probably more complex. And I think the complexity also lies not just in what might be happening to somebody's brain, but also to what's happening around that person as well, and all of the things we've talked about -relational selves, and how we understand and make sense of what's happening, and then how people interact and environmental factors. And so, there is a role for understanding that difference by a kind of very neuroscientific sort of understandings. But my inclination is that it's kind of more complex than that as well. And that doesn't explain everything. And we know that there are people who have plaques and tangles on their brain that show up postmortem, who've not had a dementia. And so, the kind of relationship between what's happening in somebody's brain and what was sort of being manifest is is again, more complicated.

**Helen Pleasance**

I really recognised what you were saying in your description of the woman in the care home. Not that my mum would have sworn. That there was somebody who still had a really rich life and it was a very rich linguistic life. To the end it was jokes and where she trawled it up from memory, she trawled up an old music hall song that, you know, she suddenly started singing to my brother and me and we googled it, and we'd sing this song, ‘Ginger, you’re barmy, get your hair cut!’ She’d never sung this song throughout my whole life, you know, it was almost like tuning into a 1930s’ radio station or something. The question, for me, is how, as a creative engagement with dementia, can we do something with that to make the lives of people with dementia better, I suppose. Yeah, the whole kind of lockdown of last year just highlighted how important to people with dementia is having people around them who they can have that kind of relationship with. Once my mum wasn't seeing my brother and me and wasn't singing that song and we didn't have that shared stuff, you know, her life was massively diminished. Having notions of kind of inter subjective personhood clearly is important for me thinking about how relationships with other people are important to people with dementia.

**Lucy Burke**

But having relationships with other people are important to everybody, I think and relationships and being in an environment that supports and nurtures you, and, whatever point you are in your life, that understands and gives people space to express themselves. All of that is important. And I think the problem is that if you have a system that is built around a very narrow idea, for instance, of capacity, that kind of strips, people of any real kind of rights to access those things that make us fully human, then you are in in real difficulties. And I think the problem is that. I'd really like to build a world that starts with the people who are most on its periphery, because I am absolutely convinced that would be a good world for all of us, that actually kind of understands those things. So, I think that the interesting thing about kind of engaging creatively is often when you enable people spaces to express themselves or engage creatively, you can also change the assumptions of the people around those people. So a lot of evidence from work by people like Anne Basting's Timeslips project, which is a kind of storytelling project that she developed with people with dementia is not based on demanding that people tell stories or remember things, it's about sort of looking at images and seeing what people say, and things like that, and constructing sort of stories from that, that when you do that, and when the people who are carers see people with dementia engage, they change their ideas about what those people can do, or who those people are, and how they might express themselves. And you can kind of create an environment based on kind of mutual recognition and respect a lot more than understanding carers, for instance, feeding, cleaning, keeping alive, which is a very diminished idea of what people need and what they deserve, and what you need to have to continue to flourish regardless of where you are in your life. You know, whether or not you know, you're at the end of your life or you know, the middle of it. So, I think it's been desperate to see what's happened over lockdown really, because I think a lot, not around dementia, but about my son, and I think about sort of young adults with learning disabilities in residential care. And I was really, you know, I would have been desperate if I couldn't have seen him. It would have been heartbreaking. He is at home, obviously, with me. And it was like, you know, the idea of not being able to see somebody you love. Yeah, it must have been really tough.

**Caleb Klaces**

I wonder, maybe a point to think then about some of your more practical work, if that's the right way of putting it. I mean, you're an academic and you work in an institution. But you also, would you call yourself an activist?

**Lucy Burke**

Yeah. Probably [laughs]

**Caleb Klaces**

Okay. And recently, you've taken the government to court, is that right?

**Lucy Burke**

We didn't get to court because it was resolved. I used judicial review to challenge the guidance on critical care, the allocation of critical care during COVID.

**Caleb Klaces**

And what happened?

**Lucy Burke**

They changed it. They changed the guidance. I mean, this isn't totally dementia related, although it kind of raises interesting and important questions, I think. The National Institute of Clinical Excellence issued guidance, which encouraged doctors to use something called the clinical frailty scale, to assess whether or not people should access critical care. And one of the key characteristics of a clinical frailty scale is it's normally used for much older people living with multiple health conditions, who would be described as frail. And it's about making, I suppose, end of life decisions about care. But one of the things that it focuses on is levels of dependency, you know, how dependent are you. Are you dependent on others for daily life? Of course, if you use that with every age group, all adults rather than just you know, people who are much older, or there are questions about how people use it, and how we think about the right to life, and older people as well, which I think are really important. If you use it for younger people, there are people who are perfectly well, you know, not ill who have autism or a learning disability, or cerebral palsy or Down’s syndrome, who would potentially be denied critical care, just on the basis of the fact that they need support in daily living. And that's what was immediately obvious to anybody who knows anything and thinks about disability, but it had not been factored into that advice. And I felt, you know, that it was very important for it to be challenged. And, and it was challenged and changed, although, of course, it hasn't stopped there being things like the blanket imposition of DNRs, as during the pandemic. It hasn't stopped other kinds of guidance, which would look at things like age and so on in terms of making decisions about critical care. You know, people have talked about elder side, you know, as a problem during the pandemic, this this kind of assumption that, you know, some lives are of less value than others. That somehow, you know, every time someone says they had underlying health conditions, it's an erosion of the rights of disabled people, for instance, or people living with long term conditions to be treated as of equal value to other people. And, you know, I think that what underpins all of that is often the reduction of the value of life to a kind of economic question, like this sort of rationalization. So, what matters about someone is that they can engage in wage labour or that, you know, they go to work, that they pay taxes or they consume, I think, you know, for me, that's not what matters about people at all. And I think we are diminished by living in a culture that seems to think that that's the most important thing.

**Caleb Klaces**

Do you think that this will be seen as any kind of threshold moment? I mean, in 10, 15, 20 years’ time, looking back at the pandemic, and what we've been talking about, about what happened with care homes, but also the ways that different human lives were quite obviously valued. What do you think are the long-term implications of that?

**Lucy Burke**

You know, in places like Sweden, people were just left to die without treatment in care homes. Spain, there were stories of bodies abandoned and corpses, you know, in care homes alongside people who were still confused and left alone. There's a sort of brutality to this, you know, and you get this alongside this longer term, sort of systematic erosion of the rights of disabled people as well, you know, I mean, disabled people only got sort of civil rights in this country in 1995. And then, you know, this has been systematically kind of attacked and eroded people's right to independent living, people's right to have choices, to be able to engage, to be able to have kind of meaningful opportunities and experiences. All of those have been reduced. And what worries me is that the very sort of stark kind of utilitarian logic behind that, that kind of idea of people only mattering if they can contribute, you know, this idea of the kind of disposable humans. There are all sorts of disposable humans, you know, from people whose death in the channel is passed by, people in refugee camps, different groups of humans. But for disabled people, and older people, though, it seems to be accepted that somehow, they're disposable, you know. I’m worried that that will become unchallenged, particularly given that we're living in a moment where you've also got a kind of climate emergency, you've got this idea of kind of limited resources, massive inequalities, all of those things coming together to make a situation worse, and COVID, being the thing that really expresses that, brings that to light in a very powerful way, I worry that it could go in that direction. I really hope that it doesn't, and that actually, you know, there are enough people willing to come together to imagine something radically different, because I think that there is a radically different way of understanding all of this stuff. There is a world that we can build on the basis of the value of everybody's lives in a kind of much more egalitarian way of thinking about things. But you know, I do think COVID is such a significant and rupturing experience that it's shown us perhaps where we could go and hopefully, alternatively allowed us to imagine that we can do things very differently.

**Helen Pleasance**

Yeah, now I think that would be a moment of optimism and is maybe something to kind of finish on and yeah, just to think about. Dementia does touch everybody's lives, the relative with dementia makes you have to rethink dementia, and makes you realise that it is a part of everybody's life. And, as you say that normalising of it, making it ordinary, is something that can be quite radical in terms of how we think about just organising bigger things and things more generally.

**Lucy Burke**

I really think that, and I think ordinariness – I think that a lot about my son, I think, you know, his kind of differences are so ordinary to me, it's so a part of my life that I don’t think about it. I do think about the ways in which he's really transformed my understanding of what matters and, I suppose, some of the kinds of, of terrible things about normative social attitudes and the ways we do things, why we do things in a certain way. And I think you can kind of really understand a different kind of world if you understand it alongside a difference. If we understood that the moment when you exchange a smile, or when you laugh together, or when you sing together, or when someone stops and touches the petals of a rose, or whatever, all of those things matter and are of value, and operate outside a kind of dominant system of kind of consumption or buying things or being important or whatever. But actually, the stuff of life is those things. And I think that's really important, and that is an antidote and is a different way of understanding the world to the dominant frameworks we've had. So, I think we should be optimistic.

**Caleb Klaces**

That's a perfect place to end I think, thank you so much, Lucy.

**Helen Pleasance**

Thank you very much, Lucy. It’s been wonderful talking to you.

**Lucy Burke**

Thank you.