



## Quality in Ageing and Older Adults

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### Article information:

To cite this document:

Hannah Zeilig, Julian West, Millie van der Byl Williams, (2018) "Co-creativity: possibilities for using the arts with people with a dementia", Quality in Ageing and Older Adults, <https://doi.org/10.1108/QAOA-02-2018-0008>

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<https://doi.org/10.1108/QAOA-02-2018-0008>

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# Co-creativity: possibilities for using the arts with people with a dementia

Hannah Zeilig, Julian West and Millie van der Byl Williams

## Abstract

**Purpose** – *The purpose of this paper is to explore the concept of co-creativity in relation to artistic practice with people with a dementia. The aim of the discussion is to outline how co-creativity offers fresh approaches for engaging artists and people with dementia, can contribute to less restrictive understandings of “creativity” and above all, expand the understanding of people with a dementia as creative, relational and agential.*

**Design/methodology/approach** – *In order to examine current conceptions of co-creativity and to inform the artistic practice, relevant literature was explored and eight expert interviews were conducted. The interviews were thematically analysed and are included here.*

**Findings** – *This paper consequently demonstrates that improvisation, structure, leadership and equality are central elements of co-creative processes and outlines how co-creativity can offer fresh insights into the way in which the arts can engage people with a dementia, the relationship between creativity and dementia and the transformative potential of the co-creative arts for those living with a dementia.*

**Research limitations/implications** – *The paper discusses some of the difficulties that are inherent a co-creative approach, including power relations and the limitations of inclusivity. Due to ethical restrictions, the paper is limited by not including the perspectives of people living with a dementia.*

**Practical implications** – *This paper paves the way for future research into co-creative processes in a variety of different contexts.*

**Social implications** – *A more nuanced understanding of co-creativity with people with dementia could challenge the dominant biomedical and social paradigms that associate “dementia” with irretrievable loss and decline by creating opportunities for creative agency.*

**Originality/value** – *This exploration of co-creativity with people with dementia is the first of its kind and contributes to the wider understanding of co-creativity and co-creative practice.*

**Keywords** *Structure, Dementia, Process, Relational, Arts, Improvisation, Equality, Agency, Co-creativity*

**Paper type** *Conceptual paper*

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## Introduction

Co-creativity is a new concept in relation to artistic practice with people with a dementia. This paper traces the origins of this emergent approach. The following discussion situates co-creativity against the wider background of the role of the arts in general for people with a dementia and explores dominant concepts of creativity and how these may be understood in relation to dementia. The notion of co-creativity is then introduced as it has developed from these broader contexts. Our conceptualisation of the term has been informed by the extant literature and also a series of interviews with seven artists and one academic who define their practice as co-creative. Finally, we discuss how co-creativity is currently being practised in the “With All” project (a co-creative arts project that is taking place at the Wellcome Collection, as part of the Created Out of Mind residency). The aim of the discussion is to outline how co-creativity offers fresh approaches for engaging artists and people with dementia, can contribute to less restrictive understandings of “creativity” and above all, expand our understanding of people with a dementia as creative, relational and agential.

Received 28 February 2018  
Revised 29 March 2018  
Accepted 6 April 2018

This work is part of the Created Out of Mind research programme. Created Out of Mind was funded as ‘Created Out of Mind: Shaping Perceptions of Dementias, Grant Ref: 200783/Z/16/Z, by the Wellcome Trust as a part of the Hub Award. (Principal Investigator S. Crutch; Core Group: P. Ball, C. Evans, N. Fox, C. Murphy, F. Walsh, J. West, G. Windle, P. Camic).

## The arts for people living with a dementia

The role of the arts for people living with a dementia has been of increasing interest for academics, policy makers and artists alike in the last decade (Camic *et al.*, 2017; Kontos *et al.*, 2015; Kontos, 2018; Zeilig *et al.*, 2015). There has been a growing awareness that art and aesthetics have an important role to play in delivering healthcare as well as a reappraisal of the associations between the arts and society in general. Thus, in recent years, a growing body of international evidence has been compiled exploring the potential of the arts to impact positively on the health and well-being of people living with a dementia (Basting, 2009; Fritsch *et al.*, 2006; Ledger and Edwards, 2011). There has also been a burgeoning awareness that arts-based research methods offer alternative insights into the subjective experiences of people living with dementia (as noted by Bellass *et al.*, 2018).

In this contemporary context, arts activities for people with a dementia have flourished, including initiatives as diverse as singing, drama, visual art, photography, clowning and puppetry to name a few. There has also been an essential growth in the role of the arts for those living with advanced dementias (Crutch *et al.*, 2001). Moreover, there has been recognition of the need to privilege the perspectives and voices of people living with a dementia and the role of the arts in facilitating this (Beard, 2012; Bartlett, 2014; Hara, 2011; Hughes, 2014; McFadden *et al.*, 2008; Zeilig *et al.*, 2014). Although the evidence base requires further strengthening and is still largely under-theorised (Gray *et al.*, 2017; Schall *et al.*, 2017), it is widely accepted that both the participative arts and art therapy are important in a variety of ways for ameliorating the lives of people with a dementia (Creative Health, APPG, 2017).

The purpose of the majority of participative arts projects then is predominantly to promote health, wellbeing, cognitive function and communication and therefore they tend to focus on instrumental benefits for people living with a dementia (de Medeiros and Basting, 2013; Mental Health Foundation, 2011; Salisbury *et al.*, 2011; Young *et al.*, 2015). This is connected with the socio-political context of the arts in health that relies on empirically evidenced medical models of health (White, 2014). A “dose of the arts” is commonly given in measured amounts to people, as if the arts are carefully calibrated medications. Although there are some instances in which the aesthetic purposes of the arts are prioritised – in which the aim is to create a high-quality work of art with and for people living with a dementia (Hatton, 2014; Moss and O’Neill, 2013, 2017; de Medeiros and Basting, 2014; Dupuis *et al.*, 2016), this has not been the main focus of most arts projects. Nevertheless, the therapeutic and aesthetic objectives of a project may overlap and complement one another.

The aims and objectives of participative arts projects differ from the work of art therapists who typically work in clinical settings (hospitals or hospices) and are usually health care professionals who aim to ameliorate specific conditions (Castora-Binkley *et al.*, 2010). Thus, therapists (who may specialise in art, music, drama or visual art) tend to focus on the condition or on one particular symptom and how this can be “treated”. For therapists, the arts are employed as tools to achieve measurable ends (Cowl and Gaugler, 2014).

Although distinct in aims and objectives, art therapy and most participative arts projects for people with a dementia have primarily been focused on the beneficial and instrumental role of the arts and their ability to enhance either the health, wellbeing or quality of life of participants. The arts are often treated as functional under the assumption that they have a measurable impact on individual’s lives. The arts have had a primarily “interventionist” role (Bellass *et al.*, 2018) both in terms of the possibility that they can deliver specific quantifiable benefits for individuals and also in relation to the outputs from arts-based research. Whilst this can be a valuable and often effective approach, it is quite different from deploying the arts for their own sake, in order to engage the innate creativity of people with a dementia. The tendency to overlook the purely creative possibilities of the arts for those with a dementia is connected with entrenched ideas about what creativity is, where it is located and how it is manifested.

## Creativity and dementia

The idea of “creativity” coincided with the late Romantic period (Pope, 2005, p. 3) and was closely associated with “art” (Williams, 1988) and with the notion of the artistic “genius”. This idea of

creativity as linked to the arts and as an individual trait has been surprisingly persistent (Osborne, 2003). Even recent conceptualisations from both psychological and neurological perspectives, tend to link creative processes to specific, original and tangible acts of production that are associated with individual motivations (for instance: Csikszentmihalyi, 1997; Palmiero *et al.*, 2012). These understandings link to the myth of the “creative individual”, the “genius”, and this powerful motif often shapes social understandings of creative activities. Focusing on the characteristics and capacities of an individual defined as particularly “creative”, the narrative understands creativity as something psychologically inherent to a creative individual (Osborne, 2003) and as associated with what has become known as “Big-C” creativity (Beghetto and Kaufman, 2007). This hegemonic narrative not only informs shared ideas about age and creativity (McMullan and Smiles, 2016) but of central relevance here, also influences the ways in which notions of creativity relate (or more pertinently do not relate) to people living with a dementia. It is perhaps unsurprising then, given the intense dominance of this perspective linking creativity, as a cognitive “trait”, with the activities of particularly gifted individuals that it is not commonly associated with those living with a dementia. Indeed, people with a dementia have only recently been recognised as being routinely capable of creative activity, for instance, in terms of a myriad of everyday “little-c” interactions (Bellass *et al.*, 2018).

In the academic literature, the area of dementia and creativity has predominantly been examined neurologically or from the perspective of clinical psychology. These studies have tended to concentrate on the impact of dementias on the brain systems implicated in creativity and on visual art (de Souza *et al.*, 2010; Grettton and ffytche, 2014; Palmiero *et al.*, 2012). There is a relative lack of consideration of the non-verbal and ephemeral arts, including music and dance. A number of studies have involved the use of standardised measures of creativity as one way of assessing aspects of creative ability (de Souza *et al.*, 2010; Rankin *et al.*, 2007), these clearly present knotty problems of measurement. Indeed, the focus on neuro-scientific perspectives for elucidating the mechanisms involved in creativity and its relationship to the dementias can be both limiting and restrictive in several ways. These perspectives necessarily locate creativity as it exists within particular regions of an individual’s brain (such as the frontopolar cortex) and also highlights the ways in which brain pathology affects creativity in people with a dementia. The overall framework then, is predicated on notions of deficit and loss. The extent to which people living with dementias might contribute to a nuanced understanding of our shared creativity is mostly overlooked, as are the social, relational and emotional features of creative activity.

Therefore, we must realign our discussions about creativity, in order to appreciate the innate capacities for creativity that are evident in all people and that may be discerned in mundane, every day and shared activities (Bellass *et al.*, 2018; Osborne, 2003). We must reconceptualise creativity as collective rather than inherent to any individual and also as associated as much with process as product (Plucker and Beghetto, 2004). Therefore, creativity is not solely located within an individual’s brain but also conditioned by their relationships and wider context. This point is even more pertinent for thinking about creativity with people with a dementia. Moreover, this perspective may extend our understandings of creativity in general by disassociating it from extraordinary individuals or acts and recognising it as a more “banal process of the everyday” (Selberg, 2015, p. 157). In their recent discussion that seeks to broaden the debate on everyday creativity and dementia, Bellass *et al.* note that:

[...].. using the lens of dementia, it is possible to gain insights into how normative creativity is constructed and accounted for [...]. (2018, p. 22).

Co-creativity can add to this debate by offering a new approach for artistic practice with people with a dementia and a means of reconsidering prevailing mores about creativity.

## Co-creativity

The term “co-creativity” is nascent. Co-creativity is not defined in the OED and its borders and features remain somewhat indistinct. Therefore, there is currently no unified agreement concerning what this term refers to or how it differs from “collaboration”, “participation” or “co-design” for instance. Nonetheless, it is steadily gaining in popularity, indeed the related term

“co-creation” can be found throughout contemporary UK media. It has only recently come into use to describe a particular approach to participatory arts practice (Matarasso, 2017).

Despite the sense that co-creativity is of increasing relevance to both artists and cultural institutions alike, it seems that the approach has not been widely explored, either practically or conceptually. Of particular relevance here, it is almost completely absent from discussions about artistic practice with people living with dementia. A recent search of academic databases (ERIC, CINAHL, MEDLINE, PsycArticles, PsycINFO) revealed less than a dozen relevant papers and only three investigating issues directly related to dementia. The importance of clarifying the meaning of co-creativity is not merely a question of semantics. Once there is a lucid definition of the term we can begin to formulate its conceptual underpinnings.

To date, the more prevalent use of the term “co-creativity” has been in the business or design worlds. The emphasis in these contexts is upon the transfer of value from an end (or predefined) product to a shared process in which all those involved play an integral role in creation (Branco *et al.*, 2017; Prahalad and Ramaswamy, 2004). In these contexts, there is an emphasis on the equal contribution of all involved. However, there is also a focus on selection and filtering in which decisions are made about the most promising contributions.

The possibility that co-creation can erase distinctions between the “producer” and the “consumer” is similarly discussed in the context of arts-based projects (Matarasso, 2017). This leads to an innately democratic and non-hierarchical notion of creativity, in which the diverse capacities of all those involved are woven into the creative process. As Matarasso (2017) further highlights there is no one author, the artists involved do not instruct but rather disperse the knowledge associated with their skills, thereby privileging the creative process. Moreover, there is an important recognition within co-creative practices that creative engagement is an interactive and relational activity that creates community (HE, 2014).

Thus, although there is not currently a single agreed definition for “co-creativity” it is characterised by a number of key features including centrally: a focus on shared process, the absence of a single author or outcome (and instead the idea of shared ownership), inclusivity, reciprocity and relationality. Co-creativity relies on dialogic and empathic approaches (Sennett, 2012) in which, through the process of exchange and discussion, understandings are expanded, although discussions are not necessarily resolved. This is in contrast to dialectic encounters which tend to lead to closure (Sennett, 2012, p. 24). Co-creativity necessitates and creates openness, receptivity and imaginative space. Above all, it contrasts with restrictive notions of the lone creative “genius” that have tended to dominate views of creativity (as mentioned above). On the contrary, here creativity is understood as something that exists within and is shared by the group.

### Co-creativity in practice

In order to understand the concept of co-creativity in more depth and in particular the underlying methods that guide its practice; discussions were held with seven artists and one academic who defined their practice as co-creative. A range of informants were deliberately sought who could offer various artistic perspectives, including a musician, a dancer, a writer and poet, a visual artist and several theatre directors; the academic worked using film co-creatively with people with a dementia. These artists were contacted via existing networks (Music for Life, Dementia Positive, the Dementia and Imagination project and Dementia Services Development Centre at Stirling University). All of those who were interviewed work in community or in care home settings with diverse groups of people, including those living with a dementia. The interviews were all transcribed, coded and analysed using a process of emergent thematic analysis that was facilitated by qualitative software (Atlas.ti). This form of thematic analysis is based on content analysis, but is more concerned with patterns rather than frequency. In contrast to classic content analysis, this form of thematic analysis, as used by Dodds *et al.* (2008), draws upon empirically emergent, rather than theoretically generated themes (Searing and Zeilig, 2017). This was not about quantity, as it is a small-scale qualitative enquiry, but about the richness of the data gathered. Thus, the interviews were read by all authors and in an iterative process a number of recurring themes were identified, these were: improvisation, structure and leadership and equality. Although to some

extent they overlap with each other, they are discussed separately below. These themes constitute some of the central mechanisms underlying co-creative practice in the arts and have informed the development of the “With All” project.

Improvisation can be broadly understood as a means of using bodies, space, imagination, objects and instruments in response to the immediate stimuli of one’s environment, without preconceptions (Frost and Yarrow, 2016, p. xv). The central role of improvisation as freeing and as allowing in the moment creation, was clear for all the artists in their co-creative practice. As outlined by one theatre director:

Improvisation is crucial in terms of a way of enabling ideas to surface and a way of seeing just what can happen in the moment. (Gavin Critchon, Active Enquiry)

Indeed, the importance of emphasising in the moment interactions with people with a dementia has been appreciated in other contexts (Beard, 2012; Camic *et al.*, 2017) and has been central to the “With All” project. The work of the Elderflowers who use clowning with people with a dementia was also described as innately reliant on improvisation:

Improvisation is the basis of it all. Let’s say clowning and improvisation. Clowning, the way we use it, is where the performers connect with their own vulnerability. Because of that, they connect with the vulnerability of the person with dementia, because often people with dementia are surrounded by people in control. (Magdalena Schamberger, Elderflowers)

Therefore, to establish a “level playing field” between the clowns and the people they work with, Elderflowers use improvisation. In this context, improvisation is a means of connecting with vulnerability and allows the clowns to relate more closely to people with dementia who often feel out of control and vulnerable themselves.

Improvisation and the absence of a predetermined plan is also associated with a shared uncertainty. This can facilitate the shedding of habitual defences and roles and thus the ability to connect with others. However, improvisation necessarily involves the possibility of everyone taking risks and making mistakes, as noted elsewhere:

The hardest thing to learn is that failure doesn’t matter. (Frost and Yarrow, 2016, p. xvi).

This understanding contributes to a failure free environment which is especially important for people with a dementia (Swinnen and de Medeiros, 2018). As noted by Kontos *et al.* (2017) in their discussion of clowning with people with a dementia, spontaneity has further importance in that it:

[...] removes the normative and artificial strictures of structured therapeutic programming [...] which may inadvertently thwart creative expression. (193)

The way in which improvisation can prompt creative openness, “allowing impulses to be free” (as noted by the visual artist Lisa Carter) was apparent for all those interviewed. Although, as noted by one interviewee Dr Andrea Capstick people living with a dementia may find it difficult to “think on their feet” and require prompts as part of the improvisation process, the ability to use these flexibly and responsively was stressed. Above all, improvisation facilitates a creative immediacy and inventiveness for all those involved.

The role of structure and the closely associated concept of leadership a dominant theme that emerged from the interviews with artists. This issue overlaps with notions about the producer/consumer distinction (as outlined by Matarasso, 2017) and the extent to which these boundaries should or can be erased. If a co-creative project is a true meeting of equals in which no-one has more authority than anyone else then should there be a pre-determined structure and can there be a “leader”? The theatre director, Gavin Critchon observed that when he is co-creating theatre he makes it clear that although he understands the form, the people he works with have the content and that there is therefore an inherent co-dependency within the process. In this way, the artists provide a flexible framework (a sort of exo-skeleton) but one that can easily be re-configured and so facilitates creative participation:

It is about having a structure, but being also able to stretch and push that structure and respond to the group a little bit as well. It is kind of having that kind of stretch in there. (Gavin Critchon)

As similarly noted by the dance artist Diane Amans:

You've got to have a structure or some starting point but then noticing when someone lights up and being prepared to follow and having the [...] confidence and the disposition to actually share the leadership, lead by just being *alongside*.

The notion of structure emerged as something that should not be rigid but is rather shaped by the group and is characterised by malleability. The suggestion is that this creates a space that is freer and more suited to creative play. Similarly, the idea that leadership can be understood as being “alongside” people and is not necessarily about purposely directing the activity seems integral to co-creativity. This allows for the important possibility of change within the artistic process, something that is particularly relevant when co-creating with people with a dementia:

There is a structure within it, but it also keeps changing [...] because some people with dementia's behaviour may change quite quickly. So [...] you have to be very, very flexible. (Magdalena Schamberger)

The sense that a co-creative endeavour is predicated on and can promote a sense of equality between all those involved was repeatedly stressed by all the artists. This was eloquently expressed by Lisa Carter who said that her co-creative visual arts practice was “like being part of a sentence” with someone. This conjures up the intertwined nature of co-creative practice in which the parts are dependent on the whole for their meaning and therefore have an equal relevance. The understanding that all those involved have “equally useful” things to offer, was cogently expressed in several interviews:

Co-creativity [...] will enable us to create something very different than if we were trying to do that on our own. (Gavin Critchon)

It's very much with the aim of being a circle of equals. Each person brings something. I think then the essence is that we co-create from the centre of that circle somehow. (Lucy Payne)

The artists emphasised the different and therefore equal contributions that each individual could make to the process and how combined, this creates something wholly unique. This echoes the idea of “hybridity”, the equal grafting together of many different voices, sounds or gestures, that has been closely associated with artistic co-creativity (Matarasso, 2017). Andrea Capstick noted the growth of trust and community within a group that were co-creating together:

As time went on, the participants that we were working with actually formed into a group, [...] they were interested in each other's films and they were interested in watching them together. (Andrea Capstick)

In all the interviews, the artists emphasised their awareness that the essence of their work was about exploring and valuing the equality of all human experiences. There was a sense that this acknowledgement of equality was basic to co-creativity and offered a means of meeting with people affirmatively, where they are.

Our practice in With All has been closely informed by the insights offered by these co-creative artists. Hence, improvisation is prioritised as is the salience of play, the gathering is characterised by a flexible structure that can shift and stretch, similarly leadership is shared within the group rather than located within any one individual and the equality of each person's contribution is central.

### The With All project – co-creativity with people with a dementia

The With All project is a ten week co-creative arts project that is currently taking place at the Wellcome Hub. It comprises three musicians, two dancers and two researchers and centrally a group of people living with a dementia and their partners. Due to ethical constraints which preclude the involvement of people with a more “advanced” dementia taking part in research, the project has been divided into two phases. The first four sessions constitute a “Learning phase” and has included people who could not formally give consent. During these sessions numbers of people with a dementia have varied (due to ill-health) but have ranged from four to one. The second four sessions of the project are the “research phase” and include six people with a dementia and their partners.

Co-creativity as we are starting to conceptualise it within the With All project, shares some similarity to the understandings offered by the design and business worlds. In particular the possibility that distinctions can be erased between the “producer” (or in our project, artist) and “consumer” (or participant). However, it fundamentally differs in that the objective is not to co-design a product or work towards a single composition or performance. There is no emphasis on any particular “outcome”, neither is there a definable end-point.

On the contrary, co-creativity with the arts and with people with a dementia is unwaveringly about mutual involvement in an aesthetic process. Improvisation, play and the subsequent creation of a ludic space is central to this process. Play is an activity that has no directed or practical purpose and exists between imagination and the external world. Play has been described as opening up a space of trust and relaxation which then enables a “creative reaching out” (Winnicott, 1971, p. 75), thus play and the sort of creativity it evokes arises from both openness and formlessness. Play has been cogently theorised as essential for emotional and psychological well-being and the maintenance of a sense of self (Winnicott, 1971) but has only relatively recently been recognised as equally crucial for people with a dementia (Swinnen and de Medeiros, 2018).

Co-creativity as we have witnessed within With All, both relies on and produces a series of interdependent moments which could not exist independently. There is no one author and thus an innate equality. Moreover, there is an important recognition within co-creative practices that creative engagement is an interactive and relational activity that creates community. Co-creativity may generate group or individual compositions and moments of self and group expression that are almost but not quite performances but these are intrinsically linked as they emanate and take shape from the whole group. In this way, co-creativity can be understood both as it is synchronous and as something that necessarily takes place in the moment. This sense that there is only one time within the co-creative process is linked with the modality of improvisation (as theorized by Nachmanovitch, 1990).

Although co-creativity relies on collaboration, it must be understood as more than this – primarily because collaboration is an action that tends to also be understood in relation to the making of a product. Neither is co-creation simply participation – because this suggests that there is something unambiguous or pre-existing to join in with. In addition, in participation there is an implicit suggestion of power relationships – in which a “participant” is distinct from those who lead a group. In contrast, co-creation – based as it is on equality, involves more than simply “joining in” with a predefined activity. At the foundation of co-creativity, is the understanding that everyone has something to offer and that even apparent passivity and quiet affects and helps to direct the mutual creation. Thus, co-creativity is an innately democratic and non-hierarchical version of creativity in which the diverse capacities of all those involved are woven into a cohesive creative process.

### **Conclusion: why co-create with people with a dementia?**

As outlined in the introduction, there are a wide range of different approaches for using the arts with people with a dementia. These all have a valuable role and many have accumulated evidence supporting their benefits. However, restrictive understandings of creativity, as well as a socio-political context that has insistently associated arts with health have affected the ways in which arts projects are designed. Moreover, for a diversity of historical and cultural reasons, there has been very little recognition of people with neurocognitive disorders such as dementia, as creative agents. Yet, in other work we have found that even in people receiving palliative care, the desire to connect, communicate and create can be urgent and passionate (Zeilig *et al.*, 2016).

Co-creativity is about the possibility of using the arts together with people to enable a self-making process and the unexpected insights that this may prompt. There is an ability within the co-creative arts for people to explore uncomfortable emotional experiences (Bellass *et al.*, 2018) which are not accessed within more structured arts activities. Co-creativity with people with a dementia generates relational interactions which are not focused on the completion of instrumental tasks (such as eating, dressing, bathing, etc.) or as a means to an end (such as to increase wellbeing or physical agility). Co-creativity using the arts extends an invitation to participate in a shared and playful pursuit that allows unique opportunities for communication,



expression and glimpses into people's interior worlds. These may have therapeutic potential but this is not the goal.

There are certainly thorny issues associated with co-creativity with people with a dementia. After all, the attempt to work truly inclusively with any group of people is fraught with difficulty, perhaps particularly in terms of validating the contribution of each individual and the complexity of power relations. There are further paradoxes that are related to With All also being a research project which aims to capture and even gauge the effect of certain aspects of co-creativity (such as group involvement) with people with a dementia. We are aware that co-creativity is partly understood as a phenomenon that exists along a spectrum of possibility.

Nonetheless, the possibility that co-creativity can challenge the dominant biomedical and social paradigms that associate "dementia" with irretrievable loss and decline by creating opportunities for creative agency inspires the With All project. We are considering the ways in which people with a dementia can co-create as they are embodied, emotional, desiring, creative agents, embedded in relationships and a social context – and also some of the ways that co-creativity challenges this social context. Indeed, this work is motivated by the possibilities that co-creative practice may promote creative expression and a sense of agency for people with a dementia by privileging reciprocity and being alert to the embodied, relational nature of creativity (Kontos, 2005, 2012; Kontos *et al.*, 2017). Using the arts co-creatively also contributes to a broadening of our understanding of "creativity" by demonstrating that it is something more than a definable attribute possessed by certain individuals that results in a specific product. Co-creativity can therefore offer fresh insights into the way in which the arts can engage people with a dementia, the relationship between creativity and dementia and the transformative potential of the arts for those living with a dementia.

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