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Creating a New Performance of Dementia

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Definition. Dementia is related to almost exclusively as a biomedical phenomenon, which has led to the rise of a fear- and stigma-inducing “tragedy narrative” surrounding the condition. However, dementia does not fit into the traditional disease paradigm since dementia is unpredictable in its trajectory, varied in its manifestations from hour to hour and day-to-day, idiosyncratic in its symptomology and incurable by most scientific measures. This paradox has provided an opening for a growing movement of people around the world to argue that the most effective treatment approaches are not pharmacological, but rather social and cultural, and for understanding dementia as a socially constructed and socially performed ensemble human activity.

Key Words. Dementia, creativity, performance, improvisation, development

Creating A New Performance of Dementia

We hope our title is intriguing, and you are already wondering what a performance of dementia, let alone a new one, could be. The idea that dementia is performed derives from the premise that all human actions and social interactions are performances, from rituals to theatre, from gender to conversation. Performance in this sense is the concern of the field known as performance studies (Schechner, 2012) as well as some branches of anthropology, sociology, linguistics, literary studies and psychology (Carlson, 2004). The notion that individuals, families, communities, and the health care, medical and scientific institutions *can create new performances of dementia* challenges the approach to dementia as exclusively biomedical and individualistic. Like all illnesses, dementia is biological-social-cultural-political, all at the same time. As socially constructed, dementia can be reconstructed, again and again.

The reconstruction we are putting forth—a new performance—grows out of the recognition that human development is a social-cultural creative accomplishment in which performing “other” and “beyond” ourselves is essential. Performance in this sense is the centerpiece of the practical-critical approach to human life known as social therapeutics and the psychology of becoming (*http://eastsideinstitute.org/about/*). This chapter begins with a brief overview of this theoretical framework and methodology before turning to the specifics of the subject at hand. We introduce some specific ways that social therapeutics has been applicable and invaluable to creating new performances of dementia, including the concept of the dementia ensemble, and show the developmental potential that can grow from relating to dementia as performance for individuals, relationships, communities and society.

Social therapeutics originated in social therapy, a psychotherapy developed in the 1970s by Fred Newman (Holzman & Mendez, 2003) and currently practiced in the US and internationally. Social therapy organizes groups of people to deal with emotional distress and pain by reinitiating their emotional development /creating new emotions. In the 1990s, Newman and Holzman made the connection between play in early childhood and theatrical performance in adulthood. Both activities are instances of being “who we are” and “other than who we are” at the same time. Both activities are developmental, that is, they create something new out of what exists. Additionally, both activities are social (ensemble) activities. Newman and Holzman began to see the playful and performatory nature of the social therapy activity and deepen their understanding of both performance and social therapy. They and others who were involved in the practice came to appreciate the power of performance and play in all areas of life. Subsequently, over the decades the approach of social therapy expanded well beyond the therapy office and, by the 21st century, broadened into social therapeutics—a transdisciplinary practice of relating to people of all ages and life circumstances, in all settings, as social performers and creators of their lives. This way of relating to people activates their capacity to play, perform, philosophize and, in that process, create new ways to be, see and relate to themselves, others and the environment. Both persons and communities create their development by performing their becoming (Holzman, 2009; Holzman & Newman, 2012; Newman, 1996).

Human development and community development are possible because *human beings are never merely who we are* at any given moment. We are, rather, simultaneously who we are and other than who we are. The 10-month old baby who cannot yet speak her mother tongue can babble her way onto a conversational stage with a parent and hold her own—because she is related to by her parents not just as who she is (a baby who is not yet a speaker) but also and at the same time as other than who she is (a baby who is a speaker). She does not become a speaker by doing things we call learning or studying. She becomes a speaker through *performing* as one—before she knows how or even that she is doing it. This performatory way of being relational—of giving and creating love, tenderness, caring, commitment and joy through play, playing at, performing as other, doing what you do not know how to do—is magical, more so because it is mundane and everyday (Holzman, 2018). This understanding of development and of performance—and of how they are related—is the heart and soul of social therapeutics.

Today, social therapeutics is practiced and advanced at the East Side Institute (Institute) headquartered in New York City, and worldwide by hundreds of scholars and activists; psychologists, counselors, social workers and therapists; educators and youth workers; doctors and nurses; social justice artists and activists, and community organizers. For many of them, social therapeutics is both a new kind of psychology and a new form of social activism (performance activism) in which the social-emotional-cultural-intellectual development of persons and communities is the focus and the key to world-changing (Friedman & Holzman, 2014).

What, you may be wondering, does a focus on development have to do people at the end of life? Presumably, they have finished developing. What is more, people diagnosed with dementia are more likely to be characterized as *devolving* rather than developing. And playing and performing? Isn't the loss of self (and memory and recognition) too tragic to play around with?

As we will illustrate, the answer is a resounding "no." In the remainder of this chapter we discuss the socialness and relationality of dementia, the developmental potential (for individuals, relationships, communities and society) of relating to dementia as performance, the new unit of the dementia ensemble and how to help people build it and create new performances. We will share stories and examples from our work and that of our colleagues. It is important to note at the outset that what follows is a report from the grassroots, if you will, not from the academy. We began our work in the dementia field as practitioners and, as it progressed, we sought out other practitioners along with people with the lived experience of being diagnosed with dementia and those who care for them. Our citations and references are nearly all from the communities of people involved in and advocating for better care, in particular, care that focuses on relationships and that utilizes people's artistic and creative capacities. As we continue to expand and deepen this work, we look forward to becoming schooled in the findings of researchers who are beginning to study the impact of arts-based interventions, performance and improvisation on the quality of life.

A Brief History of Dementia

The condition known as Alzheimer's Disease (the most common diagnosis for a myriad of neurological conditions associated with a loss of one's cognitive abilities) was first described by Dr. Alois Alzheimer in the early days of the 20th century (Powell, 2019). Since this discovery, dementia—a general descriptor for the totality of these conditions that we will be using for the remainder of this article—has almost exclusively been related to as a biomedical phenomenon. It is understood as a disease that can be studied, abstracted from the person in whom it "resides," measured, researched and its manifestations generalized and codified—the DSM-5 code for dementia (or Major Neurocognitive Disorder as it is now known)—is 294.1x (Warchol, 2013).

Because the condition was classified as a form of mental illness, people exhibiting symptoms of dementia were often locked away in institutions. It was not until the 1960's, when large mental institutions were closed on a wholesale basis across the US, that dementia became visible in communities and was designated, together with other aging-related conditions, as one of the country's major social problems. As interest in knowing what dementia is and how to take care of those diagnosed grew, so too did the call for medical solutions, which resulted in billions of dollars being invested in research into its causes and cures (Powell, 2019). According to the National Institutes for Health, public funding spending for Alzheimer's Disease research in 2019 was $2.3 billion dollars (Hodes, 2018), a figure that does not include the many more billions spent by the pharmaceutical industry on discovering a specific medical cure for Alzheimer's and related dementias.

According to the Alzheimer's Association 2019 report, 5.8 million Americans are living with dementia, a figure expected to triple by 2050 (*Alzheimer's Association Report*, 2019a, p.17). It also reports that "Eighty-three percent of the help provided to older adults in the United States comes from family members, friends or other unpaid caregivers. Nearly half of all caregivers who provide help to older adults do so for someone with Alzheimer's or another dementia. In 2018, caregivers of people with Alzheimer's or other dementias provided an estimated 18.5 billion hours of informal (that is, unpaid) assistance, a contribution to the nation valued at $233.9 billion" (p. 31).

While our experience has been primarily in the United States, after speaking with colleagues in, and reading dementia studies and other care and policy information from, European and other developed countries, it is clear that the medicalized approach dominates the dementia conversation. A 2009 IMPACT study (Alzheimer's Disease International, 2009)—a 30-minute questionnaire administered to 1,700 professionals, members of the public, caregivers, payers and decision makers from five European countries—bears out this impression. The concerns expressed by the majority of respondents were primarily focused on medical issues related to diagnosis, early intervention, education and more funding of medical research (Martinez-Lage, Frolich & Knox, 2010).

For Dr. Al Power, an internationally renowned geriatrician and Schlegel Chair in Aging and Dementia Innovation at the Schlegel-University of Waterloo Research Institute for Aging in Ontario, Canada, "The narrow biomedical view has created a system of care that produces as much disability as the disorder itself" (Power, 2010, p.12). As he writes in a piece for *Changing*

Aging, the shame is "…not because there have been no significant advances in treatment, but because—from restraints, to locked units, to antipsychotics, to ECT—we have lost our recognition of the humanity of those living with the diagnosis" (Power, 2019).

The Paradox of Dementia

Perhaps one of the reasons we have "lost our recognition of humanity" is our failure as a culture to fully appreciate the paradox that dementia presents. Although classified as a biomedical condition, it does not fit into the traditional disease paradigm. Dementia is unpredictable in its trajectory, varied in its manifestations from hour to hour and day-to-day, idiosyncratic in its symptomology and incurable by most scientific measures.

This has provided an opening for Anne Davis Basting and others to argue that the most effective treatment approaches are not pharmacological, but rather social and cultural, such as arts-based therapies, theater, improvisation, exercise and social and cultural engagement. One of the most respected and creative advocates for an alternative dementia culture, Basting is a professor of theater at University of Wisconsin Milwaukee, author of *Forget Memory*, founder and president of Timeslips, a MacArthur Fellow and 2015 Next Avenue Influencer in Aging. In an article, "Why the Arts are Critical for Dementia Care," for *Next Avenue*, a national public media journalism service for "America's older population," Basting writes:

> A symbolic and emotional communication system, the arts don't rely on linear memory and rational language. Rather, the arts engage our intuition and imagination. Their building blocks for expression are movement, gesture, words,

> patterns, sounds, color, rhythm, texture and smell—to name just a few. As access to rational language falters, a person's imagination can soar. You don't need to be an artist to use the arts for expression. These tools are available to everyone. Over the last 20 years, I have worked to encourage care partners to communicate with people who have dementia through creativity. The shift from expecting and correcting memory to opening and connecting through imagination can be profound, especially for family members. (Basting, 2015).

We do not know exactly when improvisation was first used in working with people living with dementia and their care partners, but Karen Stobbe is one of the pioneers. An accomplished actor who discovered the value of improvisation in dementia care while taking care of her parents, Stobbe is developer of In-The-Moment, which supports those living with dementia and those who care for them. As she has written, "Flexibility, adaptability, courage, spontaneity, listening, generosity, acceptance…are characteristics of an excellent caregiver. They are also qualities of an excellent improvisational performer" (Stobbe, 2003).

While research on dementia remains overwhelmingly biomedical in its focus, there is a modest but growing call for research that focuses on care rather than cure. In 2018 the National Institutes for Health published, "The Arts as a Medium for Care and Self-Care in Dementia: Arguments and Evidence," which makes this point directly: "Most research effort has been focused on the search for causes and cures. However, the quest for a cure has proved disappointing so far, and some pharmaceutical companies have abandoned it altogether…Interventions that improve the functioning, quality of life and satisfaction of people with dementia are therefore in demand" (Schneider, 2018, p.1151).

In February 2019, the *Washington Post* published a front-page article, "Changing the tragedy narrative': Why a growing camp is promoting a more relational joyful approach to Alzheimer's." The Joy of Dementia workshops inspired, and were cited in, the article, which also reported that "…a 2016 pilot study in a Canadian nursing home that found dementia patients' behavioral and psychological symptoms declined significantly and their quality-of-life scores improved significantly after 12 weeks of visits by 'elder-clowns' who engaged with them using humor, empathy and improvisation. Caregivers, too, appear to benefit: A 2016 Australian study found dementia-care staff with positive attitudes and 'person-centered' strategies felt more competent about their ability to provide care" (Bahrampour, 2019).

Our collective ability to embrace dementia in its complexity is limited by the fear and stigma-inducing "tragedy narrative" that continues to prevail as the dominant response to extreme forms of cognitive decline. In Western culture, it is primarily our cognitive functioning that is thought to make us human. And this is what people with dementia lose —the ability to think, to reason, to recognize, to remember, to know. Consequently, people living with dementia are often related to as having lost their human-ness; they are no longer expected to learn, develop, adapt and connect. Yet, as devastating as the loss of memory can be, it is compounded by how it is related to by what Vygotsky referred to 100 years ago in his work with the deaf, blind and retarded as the secondary stigma located in the socio-cultural environment (Vygotsky, 1993). Similarly, according to Jennifer Carson, director of the Dementia Engagement, Education and Research program at the University of Nevada at Reno, "Alzheimer's can be a liberating event, an opportunity to fly. This is in no way to dismiss the pain and suffering that comes from dementia, but to understand that a lot of that pain and suffering comes from the response" (quoted in Bahrampour, 2019).

For creativity and performance advocates, practitioners of social therapeutics and many others who work in the field of dementia, the tragedy narrative is not only scientifically flawed and morally problematic, it is incompatible with our understanding of what it means to be human, and with the need to embrace the "other" and to relate to everyone, regardless of age or life circumstance, as social performers and creators of their lives. The Joy of Dementia (You Gotta Be Kidding!) workshop described below is a relational, person-centered and playful challenge and provocation designed to give everyone living with and impacted on by dementia the opportunity to fly and to develop.

The Opportunity of Dementia

As people living with dementia become more and more distant from the hyper-cognitive culture in which we live, they begin to express themselves in less "knowing" and language-driven ways. As nurse and author Sally Tisdale writes in "Out of Time: the un-becoming of self," for *Harper's Magazine*, "Dementia gives us an opportunity to question how time and language and perception work. It strikes me that artistic and religious practice have these qualities: new ways to use words, repetition, pauses and silences, gestures and images…" (Tisdale, 2018).

Others finding creative new ways of using words, repetition, gestures and images to humanize the dementia experience include Susanna Howard, the founder of Living Words in the UK; Dr. Richard Coaten, a dancer and dance psychotherapist in the UK; Pia Kontos, Ph.D., a senior scientist with the Toronto Rehabilitation Institute-University Health Network and producer of *Cracked: New light on dementia,* a film and educational program; Carolyn Halpin-Healy, founder and executive director of Arts and Minds in NYC; Eugenia Zuckerman, the renowned flutist whose *Like Falling Through a Cloud: A Lyrical Memoir* is a poetic rendering of her journey with dementia; Helen Abel and Eileen Moncoeur of Life Performance Coaching in San Francisco; Changing Aging and its "Disrupt Dementia" travelling show; Momentia, a collective movement that facilitates social gatherings in Seattle and Heather Hill, a dancer and dance therapist in Australia. In an article for the online journal *The Dasein Project*, Hill writes:

> In all these years of being with people with dementia, I have learnt so much about what it is to be a person…The reason that I have learnt so much…is that dementia by its very nature – as an assault on personhood – has brought me face to face with the very basics of being a person…uncluttered by all the things which make up our very Western, individualistic, cognitive-obsessed and materialistic lifestyle. It has…turned me towards relational concepts of self, that one becomes a person in relationship and continues to be a person in relationship. …It has pointed the way to not just talk of a mind/body connection (core to my work as a dance therapist), but rather of a totality" (Hill, 2011).

While the use of dance, music, theatre and the fine arts is still more prevalent than the use of improvisation, there are, in addition to Stobbe, some wonderful improvisers and improv troupes—among them Rachael Wonderlin and Christopher Wright in Pittsburgh; Katharine Houpt, The Second City and Lookingglass Theatre Company in Chicago; Taproot Theater in Seattle and Scripted-IMPROV in Massachusetts—who are working with people living with dementia.

Joining Jennifer Carson and Al Power in intervening on the tragedy narrative of dementia outside the arts are Dr. Peter Whitehouse, Professor of Neurology at Case Western Reserve and author of *The Myth of Alzheimer's* and co-author of the forthcoming *Brain Health in an Unhealthy Society*; Anthea Innes, Professor, University of Salford and Director, Salford Institute for Dementia; Jackie Pinkowitz, Dementia Action Alliance (DAA) Board Chair; Dr. Louise Aronson, professor of medicine at the University of California, San Francisco and the author of the *New York Times* bestseller *Elderhood* and Dr. Tia Powell, Director of the Montefiore-Einstein Centre for Bioethics in NYC and author of *Dementia Reimagined: Building a Life of Joy and Dignity From Beginning To End*. We are also inspired by those living with dementia who have embraced the joy of dementia, including Mary Radnofsky, a dementia rights activist and Mike Belleville, Wally Cox and Chuck McClatchey, DAA Advisory Board members.

The Joy of Dementia

The Joy of Dementia (You Gotta be Kidding!) is the name of the conversation, workshop and collective exploration of the dementia experience pioneered and conducted by two of the authors (Fridley & Massad) who felt that the group-oriented social therapeutic approach might be very helpful in intervening on the negative and non-developmental culture and experience of dementia. Social therapeutics envisions life as a continuous socio-cultural process in which ensembles (families, teams, groups of any kind) create the millions of scenes—some scripted, some improvised—of their lives. In social therapeutic environments we learn to relate to ourselves, not as individuated and isolated individuals, but as relational beings who are part of something larger than ourselves, and infinitely more complex and creative than we are generally led to believe. Thus, the creation of "dementia ensembles" as groups or communities of people that continuously create new performances of care (and life) partnering is at the heart of every Joy of Dementia workshop.

In the creation of these ensembles, we are challenging the traditional view of where disease "lives" (inside the individual diagnosed), who the "patient" is (the individual diagnosed) and on whom care and treatment interventions should be focused (the individual diagnosed). As anyone who has known, cared for and/or loved someone living with dementia will tell you, the demands involved impact on everyone, often at a very high cost. According to the Alzheimer's Association, 30 to 40 percent of family care partners—over 80% of whom are women—suffer from depression and other stress-related conditions (Alzheimer's Association, 2019b, p.34), and, for the first time, dementia has emerged as the most feared diagnosis among older Americans.

When dementia (or any medical condition) is viewed through a social or ensemble lens, the understanding of who needs help moves from the individual to the collective. This raises the need for treatment plans to include approaches and programs that broaden our understanding of support (educational or emotional) in ways that, in the words of Wally Cox, help the ensemble. The ensemble can be any size and include friends, community and family members (no matter their level of their engagement), care providers and care partners, health and social service professionals and anyone else who wants to be involved. Diagnosed with early onset Alzheimer's at age 60, Cox lives in Northern California with his wife Pat. In a 2019 talk he gave for a local chapter of the Alzheimer's Association, Wally shared his response to a doctor telling him and Pat at the time of his diagnosis to "go home and get his affairs in order."

> It was as if I was on a merry-go-round, standing on the outside edge as it was spinning resolutely, staring at the center pole where I saw the 'Big Ds' – dementia, despair, depression, disappointment and death…I was whirling in circles, becoming ill from worry, stress and the concerns I had. In the meantime, as I focused on the center of the merry-go-round and surrounding me were all the good things I would have seen if had just turned around and looked outside instead of in…I needed to look outward from the merry-go-round to see another path – the rest of my world, filled with faith, family, friends, music, love, adventure, art. I needed to recognize that I am more than my diagnosis, more than my illness…This is the path I have chosen. (Cox, 2019).

The first Joy of Dementia workshop took place in November 2017. Since then, dozens of workshops and presentations, attended by hundreds of people, have been held in New York City and other parts of the US. In addition to presenting at varied professional conferences, such as The Association for the Study of Play and the Rocky Mountain Alzheimer's Association, we have been hosted by senior day care centers, independent living, assisted living and extended care facilities, and home health care agencies (https://eastsideinstitute.org/the-joy-of-dementia/) In planning workshops, we ask host organizations to reach out to as heterogeneous a group as possible, and include those living with dementia, care partners, family members, community members, the "worried well" and medical and social service professionals. This kind of diversity offers an especially rich environment where people can play and perform together as they discover new relational possibilities.

While each workshop and presentation is different, Joy of Dementia activities share the same goal: to create the dementia ensemble. We work to create an environment in which participants, through their relational activity, gain some new ways of seeing and feeling and doing. We involve participants in activities in which they can create a more playful relationship to dementia, express the emotionality of their dementia experience and, more broadly, learn to live a more improvisational life, The workshops are playful, practically philosophical and improvisational in form as well as in content, which means that what ultimately gets created has everything to do with what the participants respond to and initiate.

Participants begin playing and performing from the beginning of the workshop, which opens with a slow motion “ice breaker” exercise in which they look each other in the eye, make funny sounds and create absurd faces. In addition to getting people up on their feet and playing, this exercise gives workshop leaders the opportunity to see how the group responds to doing something “weird.” What follows is a welcoming introduction by workshop leaders and a brief PowerPoint about the social therapeutic approach. From then on, basic improvisational exercises and games are interspersed with conversation.

The workshop participants are related to as members of a performance ensemble, that is, a community of performers who are working together to create an environment in which everyone can honestly and openly express their fears, their joys, their conflicts, and whatever else they want to say. Since a majority of those participating are unfamiliar with improvisation and generally view performance as something only professionals can do, it is important to introduce them to what it means to perform in everyday life – and to the notion that we can perform every aspect of our lives, including how we speak to each other.

One of the ways we do this is by creating "performed" conversations in the workshop, that is, conversations that focus on the process of speaking and philosophically play with assumption that we "know what we're talking about." Participants are supported to listen in the way improvisers listen (that is, for offers with which to build the scene) and to create a conversation rather than simply "express their opinion" or talk at each other. For example, after we showed a 2016 TEDx video in which Karen Stobbe and Mondy Carter talk about the value of accepting, rather than negating, the confused offers that those living with dementia often make, one of the workshop participants shared her belief that being improvisational in this way would be the same as lying. As she explained, "When my mom talks about her sister Janie being alive, I knew that telling her the truth—that Janie was dead—would be upsetting. But the thought of lying to my mom, which I was raised to never do, would upset me even more." In response, other participants talked about how lying didn't bother them or offered ways to "divert" the conversation. Sensing that participants were getting stuck in a debate (albeit a friendly debate) about truth and lying, workshop leaders suggested performing curiosity ("Tell me more about your sister") as an alternative to truth-based framing, and improvisational way to keep creating the conversation. This allowed participants to explore how they might be more playful and curious which, as another participant shared, "Would be helpful everywhere in my life."

The Joy of Dementia conversation also takes place at Institute-sponsored forums and webinars with innovators in the dementia arena, so as to expand the audience for learning new ways to see and understand dementia. The November 2019 webinar, *Forget What You Know About Dementia*, featured one of us (Fridley), and the previously mentioned Whitehouse, Howard and Coaten. In the conversation, Coaten commented, "I'd like to talk about the importance of letting go of knowing in order to connect through rhythm, through movement, through dance, through song. In my work, I'm trying to increase the possibilities for a relationship and connection and finding way new ways to really forget what you think you know about dementia because if you are in that moment with somebody and you're thinking about stuff, 'What should I do? What should I think now? What's happening here?' You're not being with that person in the way they need you to be." (https://eastsideinstitute.org/forget. (2019).

Workshop Impact

Improvisational play—with its emphasis on seeing, accepting and creating with "offers" (which can include all the stuff of life, even those things that don't "make sense" or that we find upsetting)—gives us the most humanizing shot at relating to the strangeness, the fluidity and the uncertainty of dementia in ways that promote intimacy and growth, rather than frustration and humiliation. This is important because care partners and others affected by dementia often have trouble letting go of "how things should be" and who their loved one "used to be," which can be a distancing source of pain, frustration and anger. Improvisational play is how we can most creatively go from "how things should be" to "how can we create something new"—and how we can work with those living with dementia to create a shared journey.

For example, at a Joy of Dementia workshop at a senior living community in Pennsylvania, one woman said, "I now realize that when my husband was diagnosed with dementia, I kept trying to fix everything. But I eventually realized that I couldn't fix anything. There wasn't anything I could do for him. I felt inadequate and I never want to feel inadequate." In response, we asked workshop participants (in a variation of an improv exercise called, "We made a mistake!") to stand and shout out with great enthusiasm, "We are all inadequate!", which they did with great delight. In playfully acknowledging that we are all prone to relating to inadequacy as a shameful and private secret rather than a shared social experience, others were able to share similar experiences and the group playfully decided to host a regular "Inadequacy Day" for everyone in their community.

Workshop participants typically express gratitude for the opportunity to socialize their concerns about dementia and memory loss. Many of the things they speak about are common to individuals and families dealing with these issues. But most of those participating had never spoken about their concerns out loud and certainly not within a large group or with strangers. Clarissa (not her real name) is a Caribbean-American woman whose mother with whom she had always had a difficult relationship was starting to need more care. Though Clarissa had decided to be there for her mother, it soon became clear as she spoke about the situation that she was doing it alone, even though she has many friends and a very large and supportive community. When asked about this seeming contradiction, Clarissa spoke for the first time about her conflicts about being more a part of her mother's life and the embarrassment she feels about the situation. While these feelings are still there, Clarissa has told us in a number of post-workshop conversations that she has been able to "come out" and work with friends on finding more playful and social ways to include her mom in Clarissa's life and community.

Others have shared that during the workshop they realized the ways they *had been* creative while taking care of loved ones. At a New Hampshire workshop with hospice volunteers, one woman said, "This is helping me see that I was always improvising with my mom, which is pretty exciting to realize because that means I can be creative in other situations. When my mother said something weird—not factual or true—I would go with it. I stopped feeling I had to challenge her sense of reality, which allowed us both to enjoy each other a lot more. She was not the only one who found the experience engaging. The workshop host shared with us that numerous attendees thought The Joy of Dementia workshop was "engaging, fun and enriching for a new viewpoint of working with dementia patients. They told us afterwards how much they could relate what they learned to the work they are currently doing in our community with our hospice patients…It was so much fun to learn and play all at the same time." Seeing life through a more improvisational lens can help us see that we have the capacity to choose how we want to respond in any given situation—and beginning to relate to oneself as a choice creator—can make a huge difference in the quality of our lives.

Implications/Conclusion

We began this chapter by asking "What does a focus on development have to do people at the end of life?" and "Isn't the loss of self (and memory and recognition) too tragic to play around with?" Taking the social therapeutic method into the dementia arena has convinced us that development has everything to do with the end of life and that playing with "loss of self and memory" is developmental for all. Shifting our gaze away from primarily biomedical understandings of dementia has allowed us to see this varied and ever-changing phenomenon as an opening to create new ways of performing relationality, as an opportunity for joy, creativity, development and personal growth for everyone whose lives are touched by this condition

The activity of creating dementia ensembles is at the heart of everything we do. As a workshop, a playground and a collective exploration of the dementia experience, The Joy of Dementia is, for all participants, a challenging of the individualized loss and tragedy narrative we are all socialized to. It is an experience of people being involved in changing the culture of dementia and freeing themselves and others, even if only for a moment, from a repressively cognitive world. Momentarily freed from the constraints of truth and the need to know, people have an opportunity to create new ways of giving and creating love, tenderness, caring, commitment and joy through play, playing at, performing as other, doing what they don't know how to do—all things that share more than a family resemblance to the non-knowing growing we all engaged in as babies and toddlers.

Our active engagement with the dementia change movement through workshops, conferences, written communication, the media and personal interactions, has allowed us to meet an ever-expanding network of compassionate and creative pioneers and innovators in a variety of arenas who are discovering ways to creatively upend the tragedy narrative of dementia. We have learned so much from these collaborators, including those living with advanced dementia. *The Things Between Us*, a poetry anthology published by Living Words in the UK, contains these words from a person with advanced dementia (there is no indication of age or gender in the anthology):

Seeing 1

Well I've gotten older haven't I
Supposed that's normal
I'm not very good at writing
Can't see very well anymore
But I can see you and I can

Look at things and see things
But I don't know
What they're talking about
Cos I get mixed up – But I
Recognize you right away
Feels great, trust, talk
I'm getting older not dafter
(Howard, 2014, p.47).

We end with the question, "Where will this movement lead?" If the Joy of Dementia experience is any indicator, it will lead to whatever human beings, with all our foibles and flaws, conflicts and contradictions, are able to create together. Because creating a new performance of dementia is creating a new performance of humanity.

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