

The Joy of Dementia

Mary Fridley and **Susan Massad** introduce their Joy of Dementia workshops, and explain how improvisational play – with its emphasis on seeing, accepting and creating – gives us the most humanising shot at relating to the strangeness and uncertainty of dementia in ways that promote intimacy and growth, rather than anger and shame

From that moment in 1906 when Dr Alois Alzheimer first ‘discovered’ the condition that now bears his name, Alzheimer’s and dementia (for the remainder of the article, we will use dementia as the broad descriptor) have been primarily related to as a biomedical phenomenon. Perhaps not surprising, since Dr Alzheimer was a psychiatrist and those with dementia were often hidden away in psychiatric institutions, our understanding of dementia has been overdetermined (and, many would argue, distorted) by the disease model of traditional medicine.

What has this meant for the care, prevention, research and treatment of dementia? It has meant the dominance of a ‘tragedy narrative’ that equates dementia with loss – the loss of cognitive abilities, of short-term memory, of language, of judgment and of the ability to make decisions. In other words, the loss of those qualities our western (and hyper-cognitive) civilisation has come to believe make us human. This loss model dehumanises, stigmatises and shames those living with dementia and the people who love and care for them. Little wonder social isolation remains one of the most intractable problems associated with dementia and related conditions.

Changing times

However, to quote American folksinger Bob Dylan, “The times they are a changin’.” A movement is emerging across the globe that is both calling for and creating a more person-centred, humanising and relational approach to dementia practice and policy. And its impact is being felt. Over the past five years there has been a perceptible shift in focus from ‘cure’ to ‘care’ and a greater embrace of innovative and creative practices that transform the experience of dementia for everyone involved.

As Dr Tia Powell, the Director of the Montefiore-Einstein Centre for Bioethics and of the Einstein Cardozo Master of Science in Bioethics Program in



The photos on this and the following pages show participants in The Joy of Dementia workshops in the US. Photos courtesy East Side Institute

New York City, writes in her 2019 book, *Dementia Reimagined: Building a Life of Joy and Dignity From Beginning To End*: “We invest billions in finding magic pills so we can avoid the expense of caring for those who have it...We’ll have to apply a better portion of our research funding, our care dollars, and our best thinking to the problem of providing care” (Powell 2019 p160).

We fully support this new movement and, with our improvisational Joy of Dementia workshops, hope to expand and deepen its influence and impact. For us, the question is, “How can we expect to effectively ‘treat’ dementia with anything other than improvisational and other approaches that respond with compassion and joy to something as varied, uncertain and unpredictable – not to mention as socially and culturally expressed – as dementia?”

It is becoming increasingly clear to many, including scientists and medical professionals, that medicine’s problem-centred, individualistic, reductionistic and biologically-based understanding of human distress and illness is both limited and often cruelly inhumane when it comes to conditions like dementia that don’t fit so easily into the traditional medical model.

In our view, improvisational play –

with its emphasis on seeing, accepting and creating with ‘offers’ (including all the stuff of life, even those things that don’t ‘make sense’ or which we find upsetting) – gives us the most humanising shot at relating to the strangeness, the fluidity and the uncertainty of dementia in ways that promote intimacy and growth, rather than anger and shame. It is *how* we can most creatively go from ‘how things should be’, to ‘how can we create something new with what is?’

In this article we will introduce readers to this emerging movement and to The Joy of Dementia (You Gotta Be Kidding!©); offer a description of the workshops and our method and share some of the responses we’ve received from those with whom we’ve worked.

The good news

What we have discovered since first launching The Joy of Dementia is a real opening for creativity and radical humanism in both practice and policy. We have also discovered an increasing comfort with the word ‘joy’. For example, in February 2019, the *Washington Post* published a front page article, *Changing ‘The Tragedy Narrative’: Why A Growing Camp Is Promoting A More Joyful Approach*



To *Alzheimer's* (Bahrapour 2019). We were honoured that our work inspired, and was cited in, the article, which introduced readers to just some of the people living with dementia, care partners, advocates and experts who are playfully and positively challenging the medicalisation and individuation of dementia, and the stigma and isolation it has helped to produce.

While the use of other arts (dance, music, theatre, the fine arts and more) is still more prevalent than the use of improvisation, it should be noted that there are improvisers – Rachael Wonderlin and Christopher Wright in Pittsburgh; Katharine Houpt, The Second City and Lookingglass Theatre Company in Chicago and Scripted-IMPROV in Massachusetts among others – who are working exclusively with people living with dementia.

We prefer to work with heterogeneous groups and ask workshop hosts to extend as broad an invitation as possible. Having a room filled with people with diverse relationships to dementia – those diagnosed, care partners and other family members, the ‘worried well’ (old and young) and medical and social service professionals – is our favoured audience in part because, as we are learning, they rarely have the opportunity to come together in ‘real life’. It is a joy to work with them on creating an environment in which they can say and do things together that most in the room would not have thought possible.

Who we are and what we do

We come to this work not as dementia, or even improvisation, experts but as grassroots organisers, community builders and culture changers who trained with, and are now on the faculty

Perhaps the most unique contribution we are making to the dementia conversation is our approach to, and understanding of, *development... we believe that all human beings can develop throughout their lives, regardless of age, life circumstance or physical/cognitive abilities*

of, the East Side Institute (www.eastsideinstitute.org). The institute is based in New York and is an independent international educational and research centre for developing and promoting alternative and radically humanistic approaches in psychology, education and community building.

The Joy of Dementia workshop makes use of social therapeutics, an approach developed at the institute and which has been practiced for over four decades as a group psychotherapy and as an approach to human development, learning, community building and social change.

Social therapeutics is a new kind of psychology – a psychology of becoming that incorporates play, performance and practical philosophy (‘the asking of big questions about little things’) to inspire human development/ community development through group creativity.

Perhaps the most unique contribution we are making to the dementia conversation is our approach to, and understanding of, *development*. As practitioners of the social therapeutic approach – as developmentalists – we believe that all human beings can develop throughout their lives, regardless of age, life circumstance or physical/ cognitive abilities. We see the human ability to play (with improvisation as a form of play) and perform (to be who we ‘are’ – the scripted and often narrow roles we all play – and who we are becoming) as key to this lifetime growth, emotionally, socially and intellectually. We also see the building of groups, bringing different kinds of people together to play and to create something new together, as the activity of development.

The Australian connection

One of the people who has been instrumental in the development of our work in this arena, and someone we are proud to call a colleague and friend, is Heather Hill, an Australian dance movement therapist who has worked for some 30 years in the field of dementia. From our first (of many) conversations about the lens through which she and we were looking at dementia, it was clear we had met a kindred spirit. We continue to be inspired by her uncompromising belief in the capacity of every human being to grow; the joy with which she uses movement and dance to challenge

what she calls our “cognitive-obsessed” culture and the enormous wellspring of curiosity, compassion and creativity she brings to every interaction.

While we realise there are many in Australia (and beyond) who know and respect Heather, for those who don’t, she is a dance movement therapist (a Professional Member of the Dance Movement Therapy Association of Australasia) and a consultant in dementia and aged care in Australia and internationally. She has lectured in dance movement therapy, creative arts therapy and arts-based inquiry, developed on-the-ground movement-based programs and written numerous journal articles (including several for the *AJDC**), book chapters and two books for caregivers on dance for people with dementia.

If you want a glimpse into why Heather has inspired us and so many others, we suggest an article that appears in the online journal *The Dasein Project* (www.daseinproject.com) in which she 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).

The Joy of Dementia workshops

Over the past 18 months we have led dozens of Joy of Dementia workshops for hundreds of people in New York and other parts of the US, presented at conferences as diverse as The Association for the Study of Play and the Alzheimer’s Association of Colorado and have been invited to work with residents, family members and staff at senior day care centres, as well as independent living, assisted living and extended care facilities. We have also led training with home health care agencies in New York

City. In addition to this journal and the *Washington Post*, our work has been or will be featured in the *Daily Times Chronicle* in Massachusetts, *The Palgrave Encyclopedia of Critical Perspectives on Mental Health* and on the ChangingAging website (www.changingaging.org).

Each workshop is designed for the specific host organisation and audience, though our overriding interest is in creating a space in which participants can learn how to live a more improvisational life; can create a more playful relationship to dementia; can express the emotionality of their dementia experience and get back in touch with the multitude of ways (creative, physical, poetic, silly) that human beings can and do connect. We always come in with a program outline, but what ultimately gets created has everything to do with the response of those involved.

This said, here is a brief overview of the workshops: after brief introductions by us (Mary and Susan) that include our personal and professional relationship to dementia (more below), and a PowerPoint presentation that outlines the social therapeutic approach, the workshops are radically experiential from beginning to end.

We have a list of possible improv exercises and games; but there is no fixed curriculum. Participants begin playing and performing from the very beginning of the workshop, which opens with a slow motion ‘icebreaker’ exercise in which participants 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 us the opportunity to see how the group responds to doing something ‘weird’. We often follow this activity with some type of group introduction game. We then use a variety of improvisational exercises and games, all informed by the seminal improv concept of “Yes, and...,” at the centre of which is listening and the acceptance of ‘offers’.

We relate to participants as members of a performance ensemble – a community of performers and conversationalists 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. One of the ways we do this is by directing the group on its ‘audience performance’. We ask them to perform as bored, as excited, as outraged, etc – all of which they do very well! Not only do they experience themselves as performers (in the most ordinary sense of that word), they begin to appreciate the role they have to play in creating an environment in which everyone can take risks, to do what they don’t know how to do and to generally look ‘foolish’.

At the heart of everything we do is ‘performed conversation’ – conversations that play with assumptions that we ‘know what we’re talking about’. We support participants to listen in the way improvisers listen and to create a conversation rather than simply ‘expressing their opinion’ or talking at each other. We support people to perform as talkers, listeners, conversation creators and



* For more on Heather Hill’s work, see the following articles published in *AJDC*: *Dancing With Change*, Feb/Mar 2014 3(1) 27-29; *The Adventure, Not Dementia, Club*, April/May 2014 3(2) 22-25; *Everyone Can Dance*, Feb/Mar 2015 4(1) 7-8.

philosophisers, which everyone – even those whose memory is limited – can do.

As for our own experiences with dementia, for Mary, things took a more personal turn when her mother began showing symptoms after a fall and eventually died of complications of late stage dementia two years ago. Susan is the primary care partner for her sister, who was diagnosed in 2012 and we both have friends living with dementia.

Improv and development resources

If you are interested in the improvisational activities we use, we are happy to share those we have created and also recommend visiting Karen Stobbe's website *In The Moment* (www.in-themoment.com).

The East Side Institute also offers a variety of ways for those interested in learning more about the social therapeutic approach: in-person or online, over the short-term or long-term, and as part of their personal and /or professional development.

We also host regular online webinar conversations with some of the most creative voices in the dementia arena; our November 2019 conversation, *Forget What You Know About Dementia*, was led by East Side Institute Director Dr Lois Holzman and featured Mary, Dr Peter Whitehouse, author of *The Myth of Alzheimer's* (2008), Susanna Howard, founder and Artistic Director of Living Words (UK) and Dr Richard Coaten, a dancer and dance movement psychotherapist (UK).

In 2020, we will launch a program for those interested in learning to lead a Joy of Dementia workshop and, of course, we welcome opportunities to bring the workshops to communities and facilities in Australia and across the world.

Responses to The Joy of Dementia

It would be impossible to share all the ways workshop participants have responded to us and our work, but one of the things we can say is that, across the board, participants have expressed gratitude for the opportunity to speak of their concerns about dementia/memory loss and have their questions about dementia facts responded to personally and with respect. While many of the things they talked about are common to individuals and families dealing with dementia and memory loss, most of the people we met had never expressed those concerns out loud, and certainly not within a large group or with 'strangers'.

For others, it was an opportunity to share the ways they were able to be more



■ Mary Fridley (left) is pro-bono Director of Special Projects at the East Side Institute in New York City (NYC) and a teacher and workshop leader. She co-leads two workshop series, 'The Joy of Dementia (You Gotta Be Kidding!)' and 'Laughing Matters', is a playwright and theatre director and works as a non-profit fundraising consultant. Contact her at: mfridley@eastsideinstitute.org. Dr Susan Massad is a retired physician with 51 years' of practice and teaching in internal medicine. Susan is founder of a senior theatre workshop, The New Timers, at the All Stars Project in NYC and an East Side Institute faculty member. She is co-author of *Creating An Ensemble For Performing Health*, which will appear in an upcoming book published by the Taos Institute. Susan has also written a play, *Remember? Remember!*, that deals with ageing and memory loss. Contact her at: susanmassad38@gmail.com.

creative while taking care of loved ones. As one conference workshop participant said, "I realise that I was always improvising. When my mother said something weird – not factual or true – I would go with it. I stopped feeling like I had to challenge her sense of reality".

After working with staff and volunteers at Beacon Hospice in Portsmouth and Wentworth Home Care and Hospice in Somersworth, New Hampshire, we received a note from the Beacon volunteer coordinator who organised the event: "The [Joy of Dementia] workshop was engaging, fun and enriching for a new viewpoint of working with dementia patients. Numerous attendees verbally expressed after the workshop how 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 play and learn at the same time".

Of course, we have also encountered conflicted and sometimes angry responses, many reflected in the 600-plus comments submitted by readers of the 2019 *Washington Post* article (Bahrampour). The reactions were sharply divided – everything from "This is one of the most positive and helpful articles I have ever read..." to one of the most poignant responses: "What irks me [about this article] is...the implication [that we should] just laugh about it all. Yes let's laugh that my mom...almost set the house on fire...Let's not forget *teehee*

that she doesn't know her great grandchild... yeah let's slap our knees and guffaw".

While we understand this woman's anger, what we are talking about has little to do with laughing (much less guffawing). Though improvisation is often viewed (mistakenly, in our opinion) as synonymous with 'making people laugh', laughter need not be involved at all. Improv is all about working with others to create something new with what exists, including (and given the times in which we are now living, perhaps especially) the 'crap' of our lives.

In one conversation, workshop participant Amy was pretty insistent that she couldn't be playful with her mum, who was living in the later stages of dementia in a Florida aged care home. Since Amy was also telling us that she'd like to be closer to her mum in her final months, we supported her to try something new. She later told us that, since she was in the process of selling her mother's much-loved jewellery – something she thought would upset her mum – she decided to wear the jewellery (she *never* wore jewellery) to the next visit, and to ask for her mum's help in figuring out how much she should be asking for each piece. We were happy to hear that Amy's mum really enjoyed the 'fashion show' and was enthusiastic in helping to price the jewellery – and even happier for Amy, who was thrilled to do something she didn't believe was possible.

Conclusion

We don't believe seeing life through a more improvisational lens will ensure a 'happy ending'. But we feel strongly that it 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.

It is the creating of this possibility that, for us, is the joy of dementia. ■

References

- Bahrampour T (2019) Changing 'The Tragedy Narrative': Why A Growing Camp Is Promoting A More Joyful Approach To Alzheimer's. *The Washington Post*. Available at: <https://wapo.st/2OoSC0a>.
- Hill H (2011) How About Saying Hello? Person-Centred Care in Dementia. *The Dasein Project*. Available at: <http://bit.ly/32SgvCF>.
- Powell T (2019) *Dementia Reimagined: Building a Life of Joy and Dignity From Beginning to End*. New York: Avery.
- Whitehouse P (2008) *The Myth of Alzheimer's: What You Aren't Being Told About Today's Most Dreaded Diagnosis*. New York: St Martin's Press.