Lilli Mittner/Artful Dementia Lab

INTERVJU

Pioneering Creative Care

Anne Basting about how to engage meaningfully with people living with dementia

Anne Basting pioneers a radical change in how we interact with older loved ones, especially those experiencing dementia, as she introduces a proven method that uses the creative arts to bring light and joy to the lives of the elderly. In her recent book Creative Care, Basting lays the groundwork for a widespread transformation in our approach to elder care and uses compelling, touching stories to inspire and guide us all — family, friends, and health professionals — in how to connect and interact with those living with dementia. The work of Anne Basting is increasingly being recognized by artists, researchers, health care staff, and students in the Nordic countries. Artful Dementia Lab invited her into an interview for the special issue of DRAMA *on Body, Mind, Being and Becoming about her groundbreaking work, the role of the arts in aging societies, and the role of artists for social change. Anne Basting understands the relationship between body and mind as inseparable.*

ADLab: *In 2009 you published the ground-breaking book Forget Memory. What is the problem with focusing on the past when engaging with older people, specifically those living with dementia?*

Anne: Generative communication meets a person where they are. If someone only speaks Spanish, one would not approach them and expect to have an effective conversation in Greek. If someone has memory loss, one cannot expect to have an effective conversation about the past, especially the recent past (short-term memory). Efforts at communication with people with dementia tend to focus on expediency (staff is often rushed and need answers or quick cooperation), or on healing. In the name of healing, caregivers try to refresh or exercise the memory. This can work beautifully for some people with dementia, but for others, it is alienating. It is asking them to speak a language they no longer have access to. It is asking them to perform their loss.

ADLab: *Family members and friends often do not know how to approach people living with dementia. They tell us about confusion and frustration when interacting with their loved ones. In an interview from 2019 you outlined three types of responses if someone insists on visiting their mother who passed away long ago. Can you tell us about those three different pathways, which one you favor, and why?*



Anne Basting explores theater, storytelling and other arts in eldercare. **FOTO:** https://www.anne-basting.com/about

In her book Creative Care Anne Basting describes fives mechanisms to invite ourselves and others into moments of awe through creative engagement.

- **Yes, and...** which is the core concept of improvisation
- **Beautiful questions** to trigger pathways of wonder and curiosity
- **Proof of listening** as a form of authentic, active listening
- **Rigor and value** which is the magic of the artist with a special ability to create social value
- **Connect** to each other and something bigger in the larger world

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Anne: This is a classic challenge for caregivers, especially when someone with dementia enters a question loop—asking after a parent or spouse who has passed away, or an adult child who might be "coming to pick me up." One approach that has become popular is what has been called "therapeutic lying." According to people who advocate this approach, it is better to tell a "little lie" than to potentially trigger intense emotions. Another approach that is often used out of frustration, or a noble attempt to be honest, is to respond with truth in all situations. In this case, a caregiver might say "your husband passed away five years ago." This of course might be fresh news to a person with dementia and trigger grief that would be appropriate to the news that one's spouse had just died. There is a third way, what I call the creative care approach. This is to look for the emotion inside the communication and invite story responses that can build something to hold the feelings. For example, one might ask "I don't know about your mother, can you tell me about her?" And from the stories that emerge, you can shape it into something lasting. You might identify key phrases that could make a short poem and write it down on beautiful paper. Or post it on the person's door. Or keep it (and others) in a little book attached to their wheelchair (if they ride one). The next time the person asks after her mother, the caregiver can either make a new creative artifact (perhaps a movement sequence based on the stories) or review the ones that they have made together. Many cultures have rituals of memorializing those who have passed as a way to connect to ancestors. It might help to consider these as creative incantations that memorialize and honor the ones who have gone before us.

This is co-creation—when artists work as equal collaborators on the creative process with a community, for example, of elders with dementia and their families and care partners.

ADLab: *You said in a talk from 2020 that everyone can take on the "role of an artist by transforming something into social value within a community." How can artistic community share their knowledge and practices on how to transform, how to connect, how to add value with the broader society?*

Anne: This is actually quite a complex question and depends on how each culture understands and values both the arts and artists. In the United States there can be a hesitancy for people to embrace their own capacity to be creative, to call themselves an artist or feel comfortable expressing themselves using the tools of the arts. Because the arts have been professionalized, many people respond to an invitation to artistic expression with "Oh no, I'm not creative," or "I'm not an artist." Yet creativity is really an innate, human capacity. So depending on the culture, one might need to change one's language or approach to invite someone into recognizing and building their creative confidence—their belief in their ability to play with meaning-making through words, sounds, movement, color, line, objects, whatever tools they have at their disposal. The role of the artist in this situation is to invite another person into the creative process (whether they call it that overtly or not). One does this through a simple sequence of invitation, echoing/affirming, and building until the creative moment is complete. Artists can also accumulate many such moments and build them into something larger that reflects the input of a community. The key here is that people who participated recognize themselves in the product. This is co-creation—when artists work as equal collaborators on the creative process with a community, for example, of elders with dementia and their families and care partners.

ADLab: *It makes a huge difference if we create performances for other people or together with the community. Where do you see the values of co-creating?*

Anne: Offering a performance *for* a community is a lovely thing. I enjoy going to the symphony or to my children's music recitals. In these situations I sit quietly and appreciate both the effort and mastery of artists, and the beauty of their creations. These are very valuable experiences. They calm and inspire. But they aren't the only thing that people with dementia are capable of. Knowing that your life has meaning and participating in the meaning-making process is also very important to well-being. Inviting people into the meaning-making process, into making beauty themselves, enables people to participate in and shape the world, feel a sense of identity, belonging, purpose, and growth.

ADLab: *When you invite people with dementia into creative expressions, how do you know that you are not doing harm?*

Anne: It is always an *invitation* to create. If a person does not want to do it, they should always be able to say no. Saying no to the creative process might mean that they don't look up at you, or don't respond at all. If they follow you with their eyes, they might simply want to observe the process that day. If a person is participating and has a profound emotional response, like strong crying or anger, the process is overwhelming them and not working for them in that moment. This is when I thank the person for trying and suggest that we might try it another time. I think it is very important to put such "harm" into context. Some of the drugs that elders take have side effects that are incredibly harmful, or even deadly. As far as I know, no one has ever died of poetry. Or shaping sounds or gentle movements into a story.

ADLab: *What are the challenges when the artists entering care homes?*

Anne: Care homes can be very regulated and institutional, prioritizing the efficient functioning of staff over the mental and physical needs of the residents. Artists operate outside that system. They can transform spaces, roles, objects, and people by imagining them differently. They can empower staff and residents to do the same—increasing agency and playfulness at the same time, both of which have benefits for wellbeing. I remember one instance in which I was touring a nursing home with an artist. We looked at the spaces not for their functions (here is the shower room, here is the dining room), but for their performative potential. We asked questions like "Is there anywhere where someone could be unexpectedly revealed?" (like doors with curtains on them that could be opened, or even elevator doors); "Could we paint a mural on that long wall?"; "Would that cart hold someone's weight if they lay down on it and looked like they were flying?" We knew that the staff member was opening to imagination when she said, "Oh no, you'll want the shower gurney if you want to look like you are flying."

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A challenge to artists is that they might have to accustom themselves to a level of loss that they are not used to as their partners in co-creation pass away, as eventually people do in long-term care—especially during the pandemic. A challenge to the staff when artists are incorporated into care is that they find a way to balance efficiency and play/meaning-making. They are in no way mutually exclusive.

ADLab: *In our work with Artful Dementia Research Lab we have experienced critical voices complaining that art is just nonsense and that there is no time to 'play' in the struggles of everyday routines at the care home. How do you encounter such voices?*

Anne: I hold out the palm of my hand and say, "This is your system of care, and I am going to learn it." I learn how meals and medicine are delivered (one finger), how activities are offered (another finger), how medical treatment is offered (another), what happens when someone dies, what happens when someone visits (another finger). Where the staff eats and how they take breaks for themselves (another). Then I put my other palm on top of that open palm and say "this is the artmaking. It fits right on top of what you do and mirrors it completely." And then I lift my palm up, separating them by about an inch. "And what we do is just make space for wonder and meaning by integrating creativity into the daily life of this care home."

ADLab: *In the research field of art and dementia, different professions, working cultures and ways of seeing and being in the world come together. People living with dementia might be those who are less concerned with normativity such as enacting gendered or scientific norms. How can artistic and biomedical epistemology become equal partners in such work?*

Anne: I think there are some clear points of understanding between these realms and ways of knowing. For example, if a person does not find a treatment plan to have meaning, they will likely not participate in it. If a caregiver does not believe a person has an identity or meaningful life, they will likely treat them less well. The basis of person-centered care is to discern where the person is and what strengths can be built upon to foster wellness in that moment, according to what wellness means to that person in their condition. The north star is the person themselves. In relationship-centered care, one attends similarly to the relationship between caregivers, because without addressing/meeting the needs and building up the strengths of both partners, the wellness of the individuals suffers.

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ADLab: *If the value of arts and creativity were recognized in society, people might engage differently with each other on an everyday basis. What would you say is the next step towards more artful realities and what would you suggest for artists-cum-researchers to strive for?*

Anne: I see enormous shifts happening in healthcare, which is very hopeful. There is, in general, a recognition that to achieve health/wellness, we must address the social context. The most amazing intervention/surgery in the world will not work if a person is returned to a home without heat, food, or companionship. The best care for people with dementia will not hold if we do not address a culture in which dementia is stigmatized and people who experience it also experience profound isolation and loneliness, or lack avenues for meaning-making and purpose in their lives. Despair is not a symptom of dementia. Society controls that. The arts and creativity are tools/languages that facilitate meaning-making, purpose, easing of isolation/loneliness. They enable people to experience beauty and joy. This is an essential part of health. The World Health Organization has moved toward recognizing this. Efforts with the Global Brain Health Institute to integrate the arts into its fellowships (which traditionally support medical doctors and research) is also hopeful. The international movement toward social prescribing is hopeful. In my own work with Creative Care, I see hope in the steps of integrating these tools into the training of homecare workers and family caregivers. The best next steps for artists and researchers in this area is to focus on underlying mechanisms that benefit wellbeing by engaging in artistic expression, co-creation, and appreciation. We tend to hyper-focus on impacts of distinct artistic approaches (dance does this, music does that, painting does this, theater does that), but really, creativity loses its power if you treat it like a pill and dose it for specific health outcomes. We need to identify the underlying mechanisms across the arts and the different ways of engaging in them and then lift all creative engagement into the mainstream.

ADLab: *Is there something else you would like to tell the readers of DRAMA?*

Anne: Just the fact that this journal exists and your lab exists fills me with hope as well. It is thrilling to see the growth of this field with nearly thirty years of hindsight now. I'm eager for younger people to see these approaches as both normal and powerful for heart and mind. For decades (and even continuing now) younger generations have seen working with people with dementia as depressing. When really, using creative engagement to invite elders with dementia into play and meaning-making is some of the most powerful, joy-filled work that is both purposeful and meaningful. It is more than therapeutic. It is making beauty in a world that can be frightening. It is to experience time in a new way. I am thrilled when I read my student's papers and they articulate discoveries like this. And I hope that researchers invite young people into this experience too.

Find out more by listening to:

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Basting, A. (2020). How to meaningfully reconnect with those who have dementia. TedMed https://www.youtube.com/watch?v=liqQDDfhFXQ
Basting, A. (2020). Creative Care: A Revolutionary Approach to Dementia and Elder Care. HarperOne.
Basting, A. D. (2009). Forget memory: Creating better lives for people with dementia. Johns Hopkins University Press. http://public.eblib.com/choice/publicfullrecord.aspx?p=3318496
de Medeiros, K., & Basting, A. (2014). "Shall I Compare Thee to a Dose of Donepezil?": Cultural Arts Interventions in Dementia Care Research. The Gerontologist, 54(3), 344–353. https://doi.org/10.1093/geront/gnt055