An ABC of Creative Dementia Interventions:

Agency, Best Practice & Co-Creation Part II

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Exploring Inclusive and Meaningful Artistic Collaboration

"Creativity can’t cure dementia — but it can change the way we live with it."

Introduction

Hello, it’s nice to see so many of you here today. I’d like to start with my usual disclaimer, that this forum and the experiences I will recount aren’t a result of formal research or an academic paper. I’m not a dementia expert, and I don’t claim to have all the answers, but what I do have is 39 years of facilitating creative workshops, over 15 of those years, focusing specifically on People Living With Dementia, including running an engagement programme at a museum. I’ve also had decades of in-depth conversations with carers, alongside three years as a trained social carer in Camden and eight years as a carer for my mum, who had a diagnosis of Lewy Body Dementia. I will be referencing my mother a lot, as I spent a lot of time with her as her caregiver, and many of the activities I run were tested on her first!

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Background - Royal Hospital Project

To provide some background: The idea for these forums originated from a project I am currently running at the Royal Hospital, Chelsea. The Royal Hospital, of course, is the home of the iconic Chelsea Pensioners. This coming Friday’s workshop session at the Royal Hospital will be the last of only six. I say ‘only’ because the lack of substantial or long-term funding for engagement programmes for People Living with Dementia, infuriates me. Why or why won’t funding bodies release the sort of funding that would allow programmes to run for an absolute minimum of 12 months?

Anyway, the participants from the Royal Hospital are veterans Living with Dementia who are resident in the Hospital’s on-site infirmary, otherwise known as the MTI, or the Margaret Thatcher Infirmary. We’ve invited participants from a nearby care home, Ellesmere House, who are also Living with Dementia, to join in with the sessions. The guests arrive and leave by taxi, and we host them for the two and a half hours in between.

So the project is, in effect, serving as my case study for these discussions. To pull the project together, I worked with the Royal Hospital’s Community Engagement and Outreach Manager, Marina Spiteri, Elly, the Activities and Hobbies Manager at the Royal Hospital, and

Roxy, the Activities Provider at Ellesmere House, and of course, the participants, the PLWD. Flourishing Lives also very kindly made funds available to help push the project forward. Marina and I began talking about the project back in December 2024. It was mooted to start in March 2025, then April, then July, and we finally got started in August. Marina had been making progress with the Activities Provider from a different care home, but after initially seeming very keen, she went silent, so we had to start over. Marina then found Roxy, and Roxy was also keen and very responsive; even so, we had to push the start date for the project back by a couple of weeks to accommodate Roxy's calendar, including her annual leave.

Now this isn't unusual for a project; in March 2024, I was asked by Stanley Arts, an arts venue in South London, to run a series of workshops in care homes across the Croydon area. The brief wanted 'delivery of 15+ workshops reaching 150 people in care homes and those living with dementia, to take place in the care homes and at Stanley Arts.' and that 'Work needs to take place between now (March 2024) and March 2025.'
The plan was for 'three sessions across 5 different care homes (but we can adjust as we see how it goes)' and for 'the 15 sessions to be delivered between July-December 2024.' Knowing how tricky it would be to negotiate with FIVE care homes in such a short period of time, I suggested we aim for five sessions each across three care homes. Because funding for the project was based on reaching 150 people, Stanley Arts wanted to push for working with five care homes. In the end, because of the difficulties of setting things up, we did end up working with three care homes between July and December 2024. It can take a really long time to set these projects up, so if you're thinking of a care home project, please make sure you allow a long lead time.

So, back to the Royal Hospital project: In the planning stages, I attended two creative sessions run by other artists at the Hospital, and I spoke to the pensioners and members of the public who had attended those sessions.

I asked what they would be interested in doing and which activities they particularly enjoyed doing with the other artists. The information I got from those conversations was reflected in my choice of activities for my sessions. For instance, the very first thing we did was make polymer clay leaves and flowers, taking inspiration from some of the plants in the MTI garden.

Another activity will be making medals. We'll be using ribbons and fabric, including fabric from the pensioners' iconic 'scarlets'. Another activity is modelling poppies for

Remembrance Sunday, and as oak trees are significant in the history of the Royal Hospital, we'll also make leaf-shaped pendants. One of the Chelsea Pensioners, who attends the sessions, will relate the story of how oak leaves came to be symbolic, and this will help to further involve participants in the creation of the sessions..

Of the activities I'd planned for the sessions, the one the participants have spent the most time on has been leaf-shaped bowls made out of air-drying clay. Participants have mosaiced and painted them, and have really enjoyed seeing an attractive, usable object made by them, emerging from a lump of clay.

At the end of one mosaicing session, despite quite a few time checks, I couldn't get them to stop and leave in time for their taxis back to their own care home! We will probably not get to the other activities I had planned for this project, but that's okay. They are indicating that they are enjoying that particular activity, so in the moment, I am not going to stick rigidly to my plan. The group is co-creating the pacing and content of the sessions, and I'm happy to let it happen.

During a project I ran at Royal Botanic Gardens, Kew, one of the activities was dyeing silk scarves and squares of cotton, using indigo dye. Kew happened to have a large lump of raw indigo as part of its economic botany collection, so we showed that to the group and explained that the dye came from the Indigo plant. The participants enjoyed creating folds and patterns, the dyeing process and the reveal, the magical way in which the dyed fabric turns from green to deep indigo as the air hits it and the dye oxidises.

They enjoyed the activity so much that they asked for it to be repeated, so we did it again the following week. This time we dyed T-shirts, and the week after that, most of the participants attended the session proudly wearing their creations. I'm always happy to go with the flow: I'm like a DJ taking requests!

Back at the Royal Hospital, we've taken advantage of the sunny weather this summer and held three sessions in the courtyard garden of the MTI. Being able to do that added another layer of well-being to the activities. The sessions have been very relaxed, with a lot of chat and laughter.

When beginning a project, I do my research on the organisation, their activities, their history and so on, and I weave what I've learnt into the sessions and activities, but honestly, this is more for the carers or volunteers helping me with the session.

The idea of trying to impart background knowledge in a way that will land, whilst also giving instructions on the activity at hand to People Living with Dementia, is a little crazy if you think about it!

The activities we're doing at the Royal Hospital are based on nature and the Royal Hospital's surroundings, and very loosely based on the veterans and their traditions.
I've found that every organisation that commissions me wants activities or an outcome that relates to their organisation somehow. Of course, this is very understandable; organisations want to promote their own site, collections, galleries or whatever their agenda or service may be, and as an artist, it's helpful to be given a brief or theme as a starting point.

There is pressure from funders, and I get that too, but it can sometimes be hard to shoehorn the organisations' agenda into sessions, in a way that would be meaningful for most People Living with Dementia.

I get it, of course I do, but I've been begging organisations for some time to be content to simply host sessions for People Living with Dementia, and not get their knickers in a twist about anything else.

I think if a venue is not entirely dedicated to nature or the natural world, it should be willing to simply play host to a project for People Living with Dementia and allow their agenda to be secondary to the planned activity.

Over the years, it's become clear to me that the participants care home staff tend to put forward for activities are either the more compliant ones, or those who are in the more advanced stages of their dementia. I don't know why that is, but it's what I've noticed. It's for this reason that I suggest that organisations should be less fixated on their particular agenda.

At one point, there was a suggestion that instead of the Chelsea Pensioners all sitting together, and the guests from Ellesmere House sitting together, we mix it up, and seat veterans next to our guests to promote interaction.
I've found that whether Living with Dementia or not, people prefer to sit next to someone they know, so I'm honestly not that fussed about trying to facilitate friendships during my sessions that way. If friendships are going to happen, they can happen across the table, and they'll happen without my help. For me, it's enough that both sets of participants are there at all.

They've had to have a meal, get dressed, get into a taxi, get out of the taxi, walk to where the session is taking place, then settle down, get a cup of tea in them, meet a group of people who might seem to be strangers each time they come, then listen to me giving instructions they may find difficult to take in. If you are, or have ever been, a carer, you know just what a palaver it can be to leave the house.
It's all too much: new journey, new venue, new faces, new names, new toilets to find, new information, new skills…

It's a lot, especially for PLWD, so I say, 'Stop doing all that you're doing. Stop doing all the things, and let's just appreciate the fact that they're here. Let's not try to 'fix' every aspect of their lives all at once.' Besides, issues can arise through trying to manufacture friendships: I once had a case where, during the course of a thirteen-week project, two PLWD became quite flirty with each other, which I originally thought was quite 'sweet'.

In the end, the wife, (who was also his carer) of the gentleman, became very distressed and hurt about her husband's flirting. I've also had a case where a gentleman Living with Dementia couldn't be seated next to women, because he was apt to get handsy and upset them. People from the same home or day centre don't even like to sit with other people from their own home or day centre. So no, I don't make seating arrangements a priority for facilitating developing friendships. As I said, if friendships are going to happen, they're going to happen.

I concentrate on creating a relaxed atmosphere with some activity thrown in. Atmosphere first, activity second. The outcome I want from this gathering of people, is a feeling of well-being, a sense that people have had a good time away from their every day, that they've had a change of scenery, and would like to come again. If in the process of this good time, we end up with some beautiful artwork, poetry, or music, then 'Hurrah'. If not, we all still had a good time.

I had a different activity planned for each session, but so far we've only completed one, and half completed another. The group has been enjoying making leaf-shaped bowls out of air-drying clay and mosaicing on top of them. In fact, two weeks ago, I couldn't get them to stop the activity in time to get their taxis, which had been pre-ordered. I kept giving time checks, but they'd ignore them.

I heard later, the taxi driver was very irritated at being kept waiting. That impatience shown by others towards people with mobility issues, or who can't move fast, is, by the way, just one of the barriers to participation that PLWD and carers experience. I suppose people with disabilities and older people in general experience a lot of impatience in their interactions with people.

I think the Royal Hospital project shows that by working collaboratively and showing some persistence, PLWD can be supported to continue experiencing some of the things they did before their diagnosis, such as visiting friends, getting on the bus, enjoying outside spaces, learning new skills, and meeting new people.

I would like to think that this project will inspire other care homes, day care centres and organisations to think about making friends with each other, not as a box-ticking exercise, or to meet their KPIs or placate funders, but as a way of building communities of friendship and engagement.

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Creative Interventions

Defining 'Creativity' and 'The Arts'

When I speak about creative interventions, I usually mean something to do with the arts, so what are 'The arts'? Google tells us that "The arts" refers to the broad spectrum of human activities that involve creative expression, the application of imagination, and the creation of works to be appreciated for their beauty, emotional power, or conceptual ideas.

This includes activities such as visual arts (painting, sculpture), performing arts (music, dance, theatre), literature, and film, encompassing diverse media and methods of expression.

The arts are also seen as a vital part of culture, society, and the economy, contributing to job creation and public well-being, and are explored philosophically through aesthetics.

According to Wikipedia, the arts can employ skill and imagination to produce physical objects and performances, convey insights and experiences, and construct new natural environments and spaces.

This opens up an arsenal of creative weaponry at my disposal, with which to make an impact. Even if I don't possess the skills for performing all of the arts, I can find small ways to incorporate them while I'm performing the skills I do have.

Architecture

Ceramic Art

Design and Crafts: The application of creative skills to functional and artistic objects.

Drawing

Film and Photography: Creating and appreciating visual stories and images.

Literature: Written works such as novels, poetry, and plays.

Music - Music alone has so many genres and many different ways in which it can be used. Music can have cognitive benefits. For instance, we know that research suggests that when words are sung, they are better remembered than when they are spoken. (Simmons-Stern et al 2010).

For PLW Alzheimer's Disease, might it be possible to impart information to them in this way? I have many examples of PLWD in my sessions who sing almost incessantly, sometimes using it as a way of communicating or deflecting from their inability to articulate their thoughts.

Poetry and thoughts can be used as lyrics and set to dub music, as practised by Ronald Amanze, who is himself a Person Living with Dementia, and who facilitates music workshops.

Or there's Wigmore Hall's Music for Life strand, online, in person and in care homes, where participants are invited to choose from a range of percussion instruments and join in to a background of chamber music.
Manchester Camerata run a similar programme called Music in Mind.

The Performing Arts: Music, dance, theatre, and drama.

Visual Arts: Painting, sculpture, drawing, architecture, textiles

I'll add **Reminiscence or Life Story** work to this list, because, done right, reminiscence can encompass drama and theatre. Reminiscence or Life story work can get a bad rap and many people reject it out of hand, with their reasoning being that there's no point in delving into a person's past, when we should be concentrating on the present day and the here and now. Well, firstly, I don't agree with them because I think that if a PLWD's strongest memories are in the past, particularly if they find their present reality confusing or distressing, why not explore a less confusing time with them?

Reminiscence looks beyond the symptoms of dementia and focuses on what makes a person unique. It involves taking time to find out about many aspects of a person's life, including their childhood, family, the jobs they did, their hobbies, routines, preferences, attitudes, values and personality, and how these helped shape them.

I'm a huge fan of Pam Schweitzer and her Remembering Yesterday, Caring Today sessions. People who dismiss reminiscence haven't seen it done the way Pam Schweiter does it. She is able to elicit the most beautiful memories and recollections, and because she insists the carer accompanying the PLWD be a family member, you can actually see the carer/cared-for relationship going back to a parent/child or spousal relationship, because caring takes a toll and switches the dynamics of the relationship. Through RYCT, both the PWLD and their family carer recall (or learn something new about) their life before the diagnosis and respect, love and affection take the place of the tiredness or resentment that can often creep into the carer/cared-for relationship.

Can Creative Interventions Help Alleviate Loneliness and Stop Us Getting Ill?

Dementia may affect memory, but it doesn't erase creativity, joy, or connection, and we have the power to make every interaction count. Creative interventions can help us do that.
I strongly believe the arts, as they relate to health and well-being, should receive as much funding as clinical or medical interventions do. I saw this on a LinkedIn post: " An arts-on-prescription project has shown a 37% drop in GP consultation rates and a 27% reduction in hospital admissions." And this is from the All-Party Parliamentary Group on Arts, Health and Wellbeing's short report: "We are calling for an informed and open-minded willingness to accept that the arts can make a significant contribution to addressing a number of the pressing issues faced by our health and social care systems".

I come from Ghana, and before my mum moved in with me, she lived in Ghana with my younger sister. My dad died many years ago, and my mum would move in with whoever had just had a child in whatever country, stay for a year or two, then move back to my sister in Ghana. I would visit Ghana once a year, and would receive a list of things to bring with me: 'Bigsis (that's my family nickname), please bring a shirt for my pastor, a scarf for Mrs. Addo in my women's group, and Moses has been helping me a lot, so please bring him gardening tools.' Each year, I would get all the things on the list, grumbling and moaning the whole time.

Then, suddenly, one year, it hit me: A shirt here, a scarf there, that was nothing compared to what my mum and I were getting in exchange. I realised that even though my mum lived with my sister, she still needed a community. If she couldn't get to church one Sunday, the pastor would call round with some of the women's group to check she was okay and to pray with her.

Moses didn't need to help my mum out, but doing so meant he could keep my mum company and perhaps run some errands for her. My mum was being cared for by all these people, like the woman who walked around the neighbourhood every day, selling tomatoes from the basket on her head. If she didn't see my mum sitting on the verandah two days in a row, she'd think nothing of popping in to make sure she was okay and would throw in a few free tomatoes into the bargain. In other words, mum had a community of care, and in some ways, I think that might be part of the reason we didn't recognise the symptoms of her dementia earlier.

I believe she was so well cared for, outside of formal care, that it supported her to live her life well. If we can build informal care by way of communities, and some of that care centres around creativity, we could help prevent loneliness, isolation and illness.

If we can build functioning and thoughtful communities of care where we live, only people who need extremely specialised medical care will enter residential care in the first place. When I managed the London Arts and Culture Dementia-Friendly Venues Network, my mantra was 'Collaboration, not competition.' There's so much that could be done to produce dynamic programming for PLWD, and in many cases, what benefits PLWD, benefits others with neurodiversity or cognitive differences, and that has to be a good thing.

I wish organisations and venues would work on collaborating more with each other and on programming community and dementia-friendly content, which could benefit those audiences year-round. I have a dream of a programme or a 'trail', for instance, that starts with a visit to Hampton Court Palace for a project on Henry VIII say, then on to watching Six, the musical about Henry's six wives, then a visit to the National Portrait Gallery for a tour of paintings of the Tudors, then perhaps segue into a visit to Kew Palace, the home of George III, take a tour of the palace and the gardens, then a workshop on kitchen gardens, herbal remedies, or whatever.

Why Creative Interventions Matter and the Benefits of Inclusion:

- Creative interventions encourage self-expression and preserve identity.
- Creative interventions are as much about relationships as they are about art.
- Creative interventions celebrate the abilities and creativity of people living with dementia.
- Creative interventions enhance quality of life.
- Creative interventions challenge stereotypes about dementia.
- Creative interventions can build meaningful social connections. I've met many PLWD and their family or professional carers, who have formed strong bonds and social connections with each other and meet socially or sign up for the same activities.
- Research has shown that creative interventions can have behavioural benefits for PLWD, such as the ability of music to decrease behaviour that challenges.
- Creative interventions may have some psychosocial benefits, actively promoting well-being and social connectedness, where the PLWD is valued as an individual.
- Carers report that attending creative activities together improved relationships with those they cared for and provided an opportunity to enjoy a shared experience.
- Creative interventions are thought to enhance communication, brain function, social interaction, tactile processing, and sensory stimulation, as well as comprehension, hand/eye coordination, and strengthening the hands.
- Creative interventions with PLWD often take place in care homes, day care centres, community spaces, churches or cultural spaces, but they could be opened up to other spaces. The move by venues such as theatres and cinemas to provide dementia-friendly or 'relaxed' activities is creating more choices and opportunities for PLWD to engage with these activities.

Testimonies and Feedback

1. Some years ago, I spent six years running workshops in Mile End Hospital. On one occasion, after a session on Jubilee Ward, I went to the front desk to ask a member

of staff to help ‘Arthur’ back to his bed and commented that he had enjoyed playing with our diabolo toy.
A doctor who was making notes looked up and said, ‘Don’t you mean Albert?’ I said, ‘No, I’m pretty sure it’s Arthur.’ The doctor said, ‘This I’ve got to see,’ and followed me back to the day room. He was astounded to see that ‘Arthur’ was indeed playing with a toy and engaging with us.

The doctor stood watching for several minutes, then went to fetch other members of staff to come and observe this ‘miracle’. While it was delightful for us that patients were engaging in this way, what we hadn’t realised was that for some of these patients, including ‘Arthur’, our sessions constituted more engagement and communication than any of the staff had ever seen from some of them. This wasn’t a failing of the medical staff, but a clear indication that traditional or clinical medicine often only half paves the way to wellbeing, health and recovery, and that creative interventions should be put on prescription and considered an essential component of any healthcare package.

2. Participant - When I first came in and saw the brushes, I was a bit dubious; I’m not artistic. But as I got going and everyone’s work was praised and we were made to feel special, I quite enjoyed it. I got a bit messy, which I quite enjoy! You can show it off on your fingers! Everyone was very friendly and the company is good.

3. Participant - It was my first experience. I’ve never taken part in anything like this before, and I loved it. It is the beginning of good pleasure for me. I love it and I will continue at home.

4. Participant - This is something I have done for the first time. It was very interesting what we did. It makes your mind more creative and gives you more ideas and thoughts.

Common Challenges and Barriers to Participation in Creative Interventions, and How to Overcome Them

Pathways To Inclusion:

Whilst we know the benefits of creative interventions, we also know that there are challenges and barriers to PLWD engaging in them. Encouraging residents to participate in scheduled activities can be challenging, with lack of engagement being a common problem.

It can be deflating to have the effort you've put into planning and designing an activity seemingly have them ignored or dismissed. So often, low participation isn't about the activity itself but about unseen barriers you might have to dig into to identify. Happily, many of these barriers can be overcome with the right approach and gentle motivation.

Some barriers preventing engagement could be due to dementia, but some might simply be the PLWD's personality or how they are feeling in that moment. When engaging with PLWD, it is important not to assume that every behaviour, reaction or interaction is a function of a dementia diagnosis. It is tempting to go straight to dementia as the root cause of every issue, but it's also important to remember that, like anyone else, PLWD have valid emotions, beliefs and attitudes that should be acknowledged and recognised.

Of course, co-creating the creative sessions you hope to provide, with facilitators, participants, PLWD, activity providers, volunteers, and community and engagement managers, can be the start of encouraging participation, as co-creation gives a feeling of agency, ownership and inclusion in the activity.

Some barriers to participation are:

1. Language - You could invite a family member to join the activity a couple of times, or consider finding a volunteer who speaks the PLWD's language and can help out. My mum had been deafened by the illness that years later ultimately led to a diagnosis of Lewy Body Dementia, and as neither she nor any of her friends and family could sign, ninety per cent of our communication was in the form of notes in notebooks and on our phones and a few homemade flash cards.

   As children, my siblings and I were teased in Ghana because our parents always spoke to us in English, so despite the fact that between them they spoke four Ghanaian languages, we couldn't speak any. My mum received a diagnosis of dementia, and lo and behold, she only speaks to me in Twi. She would also speak Twi (our language) to most strangers, especially if they were black, and I would have to remind her to speak English so she could be understood.

   So it's also always worth checking that the person has no visual or hearing problems.
2. PLWD can feel inadequate, thinking they're too old or too unwell, for example. They will often have a fragmented view of their world, bringing their sense of self under threat if they are made aware of things they can no longer do or have difficulty doing, and our responses must not exaggerate the effects of the disease on the person.

I have often engaged with PLWD who will proudly recount their ability to play an instrument, draw or knit, but when asked to join in with any of those activities, though, some might admit to not being able to do them any more, but many will cry off taking part and may even get distressed at the suggestion that they try.
You could emphasise that their previous skills and capabilities could be an advantage in taking part in the activity.

Having said that, some PLWD will welcome being introduced to a new activity to take the place of the skill they have lost.

My mum was a home economics teacher and was a fantastic cook and baker; she could knit, crochet, sew, decorate cakes, she had green fingers, and many other creative abilities.

After her diagnosis, I did my best to facilitate her doing all those things, but apart from cooking, she never really wanted to try her hand at any of those things. In desperation, I tried adult colouring books, and for the next eight years, she did that every single day and cost me a fortune in Sharpies and new books. So it can be worth trying alternative activities until you find one that appeals.

In my sessions, I like to encourage people just to come along, watch and be in the room where the activity is taking place or try involving them in the activity another way by asking them to hand out materials or perform some other task.

If there is another participant they're friendly with, I might suggest that they sit next to them. Once the activity has started, I might ask if they'd like to join in just for a little while. Sometimes this works, sometimes it doesn't, but it doesn't stop me from continuing to try and involve them.

3. Fear of embarrassing themselves could be another factor preventing a PLWD from taking part in activities. Whether Living with Dementia or not, many people, including myself, find themselves wary of making a fool of themselves or not quite fitting in. This can be especially true of creative or physical activities. A facilitator can help by reassuring the person by joining in yourself and perhaps showing some vulnerability.

   People are quick to say things like 'I can't even draw a straight line.' I reply with 'Neither can I; that's why we have rulers.' I might go on to tell them about all the creative activities I'M not very good at, such as knitting, crochet, sculpting, playing an instrument, and so on. I might also say I'll 'partner' with them, so they might pick the colours and they can apply them.

Sometimes embarrassment might not be over actually physically taking part, but rather, over not being able or quick enough to make a decision, or to articulate it in a large group.

4. Worries about Falling Behind. It may be helpful to reassure a participant that there is no rush to finish an activity and that the activity can be shortened or simplified for them. Keep offering gentle support and encouragement.

5. Being Unaware of the Benefits of Taking Part - Sometimes, residents need to understand why they are being asked to take part in an activity. You could talk to them about the social and cognitive benefits, or you could ask a physiotherapist or other team member to help explain how certain activities support mobility, memory or mood.

6. Problems Adjusting to Residential Life or Change in Environment - A diagnosis of dementia can be devastating for some people, knocking their confidence and making it difficult to adjust to their new normal. They might struggle to adjust to being a resident in a care home or attending a day centre. It's a good idea to be mindful of this and allow them some time. Try engaging them in small activities at home or in their room every now and then. When you have created connection and trust, you can try inviting them again to join the main group.

7. Pain or Depression - If you suspect a PLWD might be feeling depressed or low, raise this with their carer to be sure. Addressing the issue could make a difference in their motivation and mood, but be mindful that depression, low mood or social withdrawal can sometimes be just that, and in no way related to dementia. The distinction can be hard to make, but keeping an open mind and not making assumptions can be important in getting to the root of the issue.

   A couple of weeks ago, one of the Pensioners who was a regular didn't attend the session. When I saw him the following week, I asked him why he'd missed a session. He quietly explained that he had been struggling with PTSD as he always did at this time of year. I shared that during the winter months, I struggled with Seasonal

Affective Disorder (SAD) and that the sunnier months with their longer days help me feel better. He explained that his feelings weren't to do with the seasons, but with the dates. He had experienced many difficult events during these particular months. This was a sharp reminder to myself not to make assumptions.

8. Peer Conflicts - As detailed above, like most of us, PLWD might simply be uncomfortable sharing space with a person they don't like or with whom they've had a conflict, which is understandable. You could try putting name cards on the table or simply showing them where to sit.

9. Brain-Damage-Induced Apathy, a loss of motivation or having no Interest in Socialising - A PLWD might be shy or simply disinterested in being sociable. If this is the case, it is important to respect their feelings. I'm not living with dementia, and I'm not particularly sociable. In fact, sometimes I go out of my way to avoid being with people.

   My mum, for instance, was pretty apathetic about almost everything other than watching football and reading the papers. She simply had no particular interest in socialising outside the house. If you brought an activity to her (as long as it wasn't physio or exercise of any sort), she would happily hold court, but leaving the house simply wasn't for her. I did manage to get her to quite a few activities, like taking her with me to my workshops and attending reminiscence sessions, which she enjoyed, but it was definitely something I had to work on.

   I remember reading about a family carer who said that when her mother was diagnosed with dementia, all her interests seemed to disappear and only her faith remained. My mum was the same; her father had been a pastor, many of my cousins are pastors, and my mother had always encouraged us to go to church. So when she came to live with me, finding a church nearby was very important. However, in her final months, I noticed she had stopped reading her bible, and that really saddened me.

   A PLWD may have no interest in what is happening around them because their current situation doesn't jibe with a reality, which, for them, may be based on memories of being much younger. These memories can influence their behaviour and how they make sense of the environment. It is worth trying to find out about their back story AND life story.

By appealing to a PLWD’s sense of purpose and asking them to help with simple tasks like setting the table up for the creative intervention, organising the supplies or sorting materials, helping with a group cooking activity, or even helping one of their peers with something, it could lead to feeling useful and more invested in the activity.

As in Problems Adjusting to Residential Life or Change in Environment above, try working with the person on a one-to-one basis, or invite them to join a session in a smaller group.

Motivating People Living with Dementia to Take Part in Creative Interventions

Motivating a PLWD to engage in social or creative activities is often an ongoing process and effort must be given to continuing that process, with the objective being to attempt to create a structure for them and a reason to get up in the morning and face the day, if not with enthusiasm, then with optimism.

Motivation can fluctuate for a PLWD, whether they are living independently or are in day or residential care. Changes to their independence, health, living environment, or circumstances can all play a role in a loss of interest in life and a lack of motivation. But by gently persisting in trying to motivate them, you can help bring back a spark in them.

Gentle Persistence Can Pay Off

Keep inviting, keep showing up, and keep offering ways to participate—without pressure. Over time, even the most reluctant resident may surprise you. Beneath it all, most people want to connect, contribute, and feel part of something.

However, the focus should be on supporting PLWD to live each day as well as possible, but without pressure. It is also important for PLWD to be able to do things without a carer and vice versa.

Co-Creation

Building experiences with participants, not just for them.

"I may have dementia, but I am still me — and I want to be heard." Person Living with Dementia

Nothing About Us Without Us

This phrase originated from the Disability Rights Movement, with the principle being that no decisions should be made without the direct involvement of those it will serve or affect. In dementia, this usually includes care planning, policy, research, and participation.

I’ve come to the realisation that, for my practice, co-creation is relatively simple to achieve and that it can be an evolving process that changes during the course of an intervention and may change again by the time I come to facilitate the next intervention. Because I am coming to the process, not as part of a consultation, or policy, research, a service or a clinical study, I can be quite loose in the way that co-creation unfolds. I see co-creation a little like a game of snowman. If we can go to the Padlet or to David’s screen, I can show you what I mean.

Slide 7

Snowman is a game where one person thinks of a word, and the other player guesses the letters that make up that word. For each incorrect guess, a part of a snowman is drawn (base, body, head, arms, eyes, nose, smile) and the wrong guessed letter is written on the side of the page, so that it can’t be guessed again. The player has to guess the word before the snowman is fully drawn.

If we can go to the Padlet or David can share his screen we can play a quick game of Snowman.

That’s how I see co-creation to some extent. Either me, or a PLWD, an organisation, an activity provider or an Engagement Manager, has an idea or an objective. Each suggestion that is thrown out results in either the drawing of the snowman being fleshed out or being put to the side of the paper. I have a turn, and they have a turn, until we get to a satisfactory place.

Slide 8

Of course I’ve also designed activities where as a group, we are very literally co-creating the work, with their final outcome being a communal piece which has the hand of every participant in it. This means that even if a participant misses one or more sessions, once the piece has been installed or displayed, they are still able to see their contribution to the piece. The piece becomes the centre of communal or group pride and a constant reminder of their abilities. I much prefer this ‘quilting bee’ approach, as the object doesn’t get relegated to the guest toilet, or the highest kitchen shelf, as some of their other creations might!

Slides 9 - 17

Here are some examples of communal co-created pieces:

Why Co-creation Matters

- Co-creation promotes a sense of agency and empowerment.
- Co-creation fosters connection, dignity, and joy.
- Co-creation creates stronger community bonds.
- Co-creation produces improved policy and care outcomes

Definitions

In thinking about part 2 of this module, I found myself wondering whether I truly understood the meanings of the words I'd used in the title, or whether I had simply chosen them as a snappy, almost click-baity title for something I wanted a lot of 'views' or 'likes' for. I decided (perhaps belatedly) to look up the words Creative, Dementia and Intervention, and these are the definitions that came up, mixed in with my interpretations of them:

Intervention:

An intervention is an intentional action to change or improve a situation by affecting the outcome and preventing it from getting worse.

Creative:

Relating to or involving the use of the imagination or original ideas to create something.

Having or showing an ability to make new things or think of new ideas.

Agency:

Agency is anything that preserves identity and encourages self-expression in a person, and by extension, fosters a feeling of empowerment.

Best Practice:

Best practice focuses on ways of helping PLWD to keep control over as many parts of their life as possible, by encouraging them to make maximum use of their remaining abilities.

It can be all too easy to focus on people's medical or social problems in isolation and lose sight of the fact that each individual is unique with very different experiences of life. Realising this can make the difference in understanding PLWD's motivations and tailoring everything from their medical care to their social activities to the person they are. In other words, not a one-size-fits-all solution, but a tailored one, or authentic person-centred care.

I am fully aware that healthcare professionals are stretched and may not always have capacity, but it is possible, over time and with persistence, to get out of the habit of tarring all PLWD with the same brush.

For me, best practice when working with PLWD is asking myself these questions and only following through when the answer to each question is ‘Yes’.

1. Is what I’m doing, is this behaviour that encourages self-expression and preserves identity?
2. Is what I’m doing, is this behaviour that builds meaningful social connections?
3. Is what I’m doing, is this behaviour that promotes a sense of agency and empowerment?
4. Is what I’m doing, is this behaviour, that challenges stereotypes about dementia?
5. Is what I’m doing, is this behaviour that enhances quality of life?
6. Is what I’m doing, is this behaviour that builds stronger community bonds?

Good; so far, so relevant. So to boil it down further, what I’m going to share with you are my experiences, thoughts and observations on ‘imaginative and original ideas for making things with people who have problems with cognitive functioning and personality changes, using intentional actions aimed at improving outcomes '.

Quite a responsibility, but let’s say I'm up for the challenge, and that by creative I mean not only ‘the arts’, but out-of-the-box or innovative thinking.

You’ll see that some of those questions crossover with some of the themes in my definition of agency. I think this crossover is important to note.

Key Ingredients

To my best practice list above, I also like to add my **Key Ingredients**. I spoke about them in part I, but I’ll quickly go through them and how they came bout for me again:

In 2024, Queen Mary University in London ran a research project they called 'Key Ingredients.' They asked eight artists, including me, to share our knowledge and expertise on what "Key Ingredients" we believe gave our workshops a therapeutic value. That project had a huge impact on me, and ever since, I have gone into my workshops wearing my Key Ingredients mindset.

1. **The Welcome** - In my role at the Museum of London, part of my remit was to manage the London Arts and Culture Dementia-Friendly Venues network.

   This was a network of venues that had been accredited as dementia-friendly by the Mayor’s Dementia-Friendly Venues Charter.

   When that role ended, me and Sam Curtis from Resonate Arts were asked to create a pilot assessment framework for the network, so we created a lived-experience panel of PLWD and their carers and sent them out as mystery shoppers to report back on selected venues such as the Tower of London and the V&A. That’s an example of co-creation, and when they reported back, we found that without exception, and to our surprise, the mystery shoppers all enjoyed and had most praise for the venues where staff were visible and welcoming towards them and were usually wearing either a dementia friends badge or a sunflower lanyard. In other words, being made to feel welcome very strongly enhanced and influenced their enjoyment of the day or the activity. That’s why ‘The Welcome’ became my number

2. **Tea and Biscuits -** Sitting down, taking coats off, taking a breath, checking out their surroundings and having a good old cup of cha. Very much part of the welcome, but also standing apart.

3. **Empathy -** Again, in a sense, part of the welcome, but it’s about recognising nervousness, shyness, reservations, even unwillingness to be in the space, and giving a discreet nod of recognition to all those feelings.

4. **Connection -** Ice-breakers usually work very well to find connections between people, and I will usually do one of many I have under my belt, but whether I do or not depends on time and sometimes on the group. There are times when the make-up of the group tells me that it’s best to just dive into the activity. However, icebreakers can be very effective: there’s one icebreaker I do that consists of passing a gift-wrapped box around the group and asking each person what they would buy for themselves if money were no object.

   People say everything from having a loved one come back from the dead to buying themselves a Porsche. On one occasion, the daughter of one of a participant said, “'After you did that icebreaker last week about the gift to yourself, and I heard my dad wistfully talking about being able to travel again, I went off and booked a Hurtigruten cruise and we’re going in December!”. I was not expecting my icebreaker to have that effect, but it just shows you the unexpected breakthroughs and special moments that can come from engaging with PLWD.

5. **Take Good Care -** This is about being aware of how your words or the subject matter at hand is landing, noticing discomfort or unease in a person, or picking up on an achievement or something that seems to resonate with participants. I will often pick a piece of work and ask the owner whether I can show it to the rest of the group. It makes them feel validated and encourages others to keep on trying, too.
   Be aware and account for the fact that the group will have varying cognitive and physical abilities, and be prepared to be both patient and flexible.

I think it’s a good idea to try creating your own list of key ingredients. They don’t have to be the same as mine; just whatever YOU feel creates the perfect recipe and therefore best practice for times when you’re engaging with PLWD.

The Opportunity

So on the one hand, we have a disease for which we currently have treatments but no cure. There are currently over 944,000 people in the UK with dementia, and that number is projected to exceed 1 million by 2030 and 1.6 million by 2050. The treatment and care of those people (some of whom may be any one of us, by the way) will fall mostly to our already beleaguered NHS and the hundreds of thousands of paid and unpaid carers.

On the other hand, we have creative health professionals, communities, and venues who can shoulder some of the strain by bringing joy, dignity, agency, and meaning to every life. We have to do it, and do it well.

Slides 18, 19

A Call to Action

Healthcare and creative health professionals need to involve PLWD in all the planning stages of their clinical and creative interventions.
As citizens, we need to advocate for PLWD by creating more dementia-friendly environments and building caring communities and joining with healthcare and creative health professionals to establish a from the cradle to the grave creative health eco-system that supports every one of us to live well, whatever the state of our health or diagnoses we might have.
Policymakers should most definitely consult PLWD and their carers directly before making decisions.

Something needs to change.

More Project Feedback

Nature and Dementia Project, Royal Botanic Gardens, Kew, Summer 2024

J, daughter of father Living with Dementia: 'After you did that icebreaker about the gift to yourself, and I heard my dad wistfully talking about travelling, we've booked a Hurtigruten cruise and we're going in December!'

J, daughter of father Living with Dementia: 'You know, we've always come here with Dad, and we walk around, and we started coming to these because we thought Dad was getting a bit forgetful, but we've enjoyed them too, and not everyone here has dementia (carers). It's just been so great.'

M, Wife of husband Living with Dementia and J's mother: 'It gives us (me and Jo) a break too. It's been wonderful.'

L, daughter of mother Living with Dementia: 'You have no idea how much these sessions have helped. My mum never wants to do things, but she loves them. They've been great and I hope you do them again.'

W, Person Living with Dementia: 'Whose idea were these sessions? They have been so good.'

W, Person Living with Dementia: 'I can't tell you how much I've enjoyed them; we all have.' 'I have to tell you that this has been so good for all of us. I hope you do them again. I will be writing to the director.' (and on and on and on, multiple times!)

Mother and daughter: 'Thank you so much. Thank you.'

P, volunteer at RBGK: I've really enjoyed these sessions. They are so interesting and they've helped me too. Just great. Thank you.'

Arts4Dementia Treehouse Project, Summer 2023

Week 4

G, wife of husband Living with Dementia: Seiwa has a way with words, making us feel that our work genuinely has some innate artistic merit.

G, wife of husband Living with Dementia: Seiwa is so good at making constructive comments about our work... highlighting the individual artistic flair from each of us in turn. We both enjoy this so much, and Dave, who has never shown an inclination to art, is in his element, very pleased with what he produced.

G, wife of husband Living with Dementia: He enjoyed it. He’s finding his love for art and a unique art style. He was tired at the start because he arrived a bit late.

G, wife of husband Living with Dementia: We loved it. We enjoyed the use of fabric. Imagining the fabric dye outcome pushed my imagination to a new space.

I, Person Living with Dementia: It was good. I feel like I learnt something new and I enjoyed everyone’s company.

A, husband of Person Living with Dementia: - I had a low mood and felt tired at the start, but I feel like the workshop was really good for lifting my mood and energy. I feel really supported by the volunteers, and I appreciate additional explanations. I actually enjoy watching the evolution of the workshops using new media/materials each session.

J, Person Living with Dementia: - I enjoyed the creativity of the exercise and the relaxing environment. The space is a bit echoey, and it's a bit overwhelming with my hearing aid, so I take them out. I need to sit at the front to hear properly.

B, daughter of mother Living with Dementia: I enjoyed it a lot. I appreciate Mum being able to jump in if we miss a session.

Z, Person Living with Dementia: I really enjoyed it this week.

J, professional carer of Person Living with Dementia: -I loved it; creative activities like this are new for me.

Week 5

D, Person Living with Dementia: I enjoyed it, but I struggled with tying knots due to Parkinson's, but I did feel supported.

G, wife of Person Living with Dementia: I loved it, the sessions really encourage D's independence, and it feels like we can both get something out of it. I love that outside of the workshops, Dave talks about them to everyone, and the sessions are helping me to discover new creative activities to do with D, like using acrylic paint.

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I, Person Living with Dementia: I enjoy doing something new through the workshop because I feel like I've forgotten so much, and I feel like I'm gaining something as replacement. It feels like I have the space to talk more and be understood for the first time in a while, in a group social setting.

A, husband of Person Living with Dementia: I is usually quiet. She's never talked so much. I loved it. Following the instructions and trusting the process allows me to be excited about the excitement! I feel like I'm floating in the sea, through to surrender.

Z, Person Living with Dementia: I loved seeing everyone happy and how encouraging everyone was while watching the outcome of last week's session. I found the fabric wrapping exercise good for me.

J, professional carer of Person Living with Dementia: The workshop was interesting because I had to trust the process and wait to see the outcome. I really loved watching the video at the start, showing the outcome of last week's session.

GM, wife of a husband Living with Dementia: "My husband and son really enjoyed today's Art and Nature for dementia session. Many thanks for a really excellent workshop." It's been lovely to see you all in action with participants, and I'm sure it's a big part of why participants seem so eager to come back.

Week 6

D, Person Living with Dementia: I enjoyed the workshop today. It was very fiddly, so it was challenging, but I'm proud of myself for finishing.

G, wife of Person Living with Dementia: I enjoy that D and I leave the workshops feeling really relaxed.

I, Person Living with Dementia: I didn't feel inspired by the soap felt exercise, so I found it difficult to stay engaged.

K, part-time professional carer of Person Living with Dementia: - I enjoyed the felt exercise as I'm really into creative activities.

Z, Person Living with Dementia: - I enjoyed everyone talking to each other. I feel like I've bonded with Gill and Dave.

Week 7

D, husband of Person Living with Dementia: I wasn't in the best mood, and I felt a bit spaced out today. I found the workshop fun, though, and I really enjoyed the different materials like moss.

G, wife of Person Living with Dementia: It felt like the workshop was chaotic, and I found it challenging on a dexterity level. Mentioned people with dementia struggle with white on white colours, and there wasn't enough contrast in colours to keep Dave's attention (potentially why Inez struggled to see as well). It was challenging for me and very challenging for D, so his concentration went a few times, and he would just go for a walk.

S, Person Living with Dementia: I thought the workshop was okay, but I'm gutted that I missed out on the fabric dyeing. I'm glad to be back and open to seeing what is left.

I, Person Living with Dementia: I like trying a new creative project that I'd never have thought to do. I couldn't see some of the close-up things, so I appreciated the additional support from volunteers.

A, husband of Person Living with Dementia: I struggled to keep up today and didn't like the fiddliness, but I appreciated support from the volunteers. I found myself getting absorbed in a task and then losing context on what to do next.

J, Person Living with Dementia: I'm not a fan of the glue, and I struggled with dexterity, but I did enjoy the concept of the workshop much more.

K, professional carer of Person Living with Dementia: I enjoyed the workshop concept and had I had to release the idea of neatness.

Z, Person Living with Dementia: I felt like the workshop was good, and I'm proud of myself for pushing myself to do folding when I was close to giving up.

J, professional carer of Person Living with Dementia: I thought it was funny making mushrooms. It was more of a fiddly workshop, so I struggled a bit. It was nice to try different things, though.

Noelle, guest: I enjoyed the workshop concept, but found the materials fiddly. I wish I'd had the materials like the underside of the mushroom top earlier, so I could have modelled the top of the mushroom on that.

Mile End Workshops

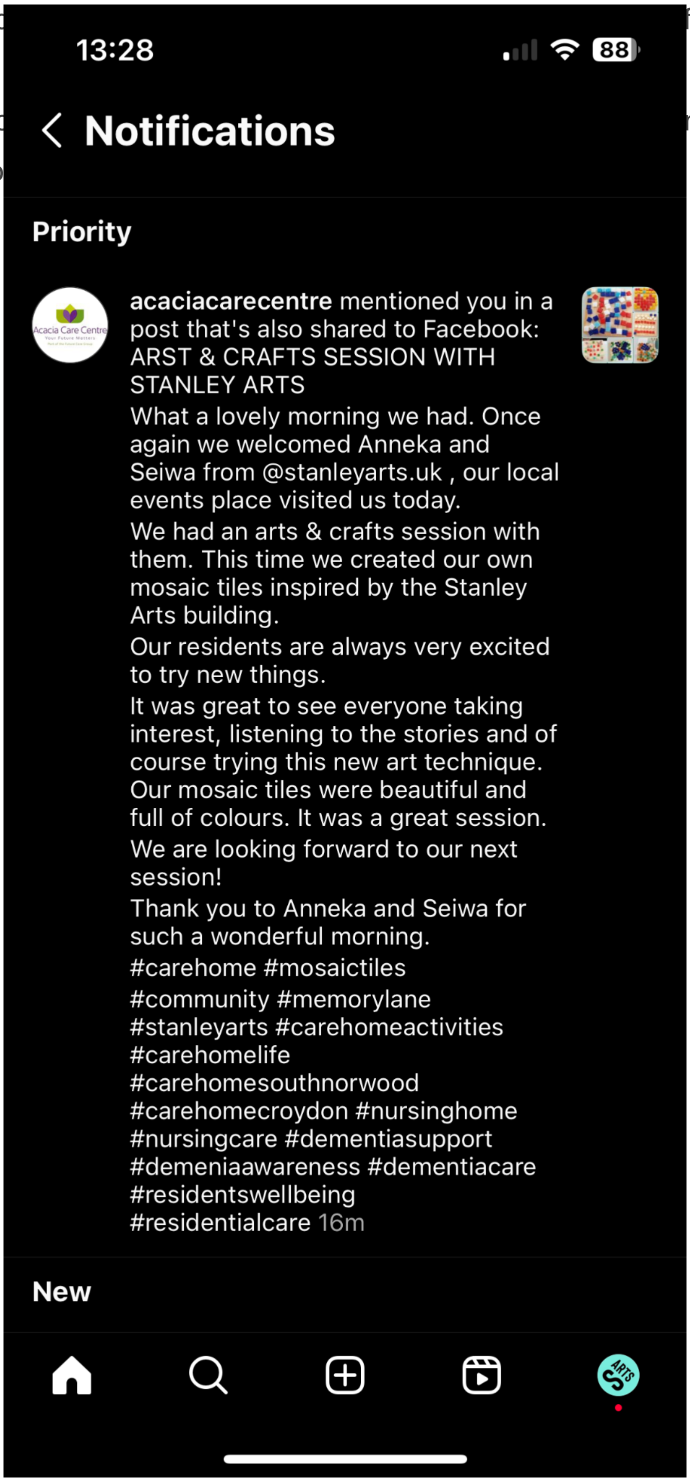
Getting feedback from staff was amazing. On one occasion, after a session on Jubilee Ward, I went to the front desk to ask a member of staff to help 'Arthur' back to his bed and commented that he had enjoyed playing with our diabolo toy.

A doctor who was writing up some notes looked up and said, 'Don't you mean Albert?' I said 'No, I'm pretty sure it's Arthur.' The doctor said, 'This I've got to see,' and followed me back to the day room. He was astounded to see that ‘Arthur’ was indeed playing with a toy and engaging with us.

The doctor stood watching for several minutes, then went to fetch other members of staff to come and observe this ‘miracle’. While delightful for us that patients were engaging in this way, what we did not realise was that for some of these patients, including ‘Arthur’, this was more engagement anc from some of them.

Unfortunately, I neglec ntend to track them down and get so

Acacia Lodge/Stan



13:28

Notifications

Priority

acaciacarecentre mentioned you in a post that's also shared to Facebook: ARST & CRAFTS SESSION WITH STANLEY ARTS
What a lovely morning we had. Once again we welcomed Anneka and Seiwa from @stanleyarts.uk , our local events place visited us today.
We had an arts & crafts session with them. This time we created our own mosaic tiles inspired by the Stanley Arts building.
Our residents are always very excited to try new things.
It was great to see everyone taking interest, listening to the stories and of course trying this new art technique.
Our mosaic tiles were beautiful and full of colours. It was a great session.
We are looking forward to our next session!
Thank you to Anneka and Seiwa for such a wonderful morning.
#carehome #mosaictiles
#community #memorylane
#stanleyarts #carehomeactivities
#carehomelife
#carehomesouthnorwood
#carehomecroydon #nursinghome
#nursingcare #dementiasupport
#demeniaawareness #dementiacare
#residentswellbeing
#residentialcare 16m

New

CREATIVE HEALTH

ARTS & CREATIVITY

Art
Music
Poetry
Literature
Drama
Theatre
Nature

HEALTH & WELL-BEING

Mental Wellbeing
Exercise
Relaxation
Cagnitive
Resilience and Confidence
Cognitive Enhancement

INTERGENERATIONAL & COMMUNITY

Carers
Community
Workplaces

SOCIAL PRESCRIBING

Gp9
Link
Workers
Care
Increased Social Pathways