An ABC of Creative Dementia Interventions: Agency, Best Practice and Co-creation - part I

Seiwa Cunningham April 2025

An ABC of Creative Dementia Interventions: Agency, Best Practice and Co-creation

Ice breaker

I’m going to go around you in the order you appear on my screen and ask you each to introduce yourselves. Tell us your name and your favourite movie of all time. I’ll start: I’m cheating a little bit, as this film is ONE of my favourite movies. It’s Fiddler on the Roof.
I watched it on the West End stage when I was 7 years old. The main character, Tevye, was played by Alfie Bass.

My parents bought the LP.

I watched the 1971 film starring Topol in 1971.

At my wedding in 2003, my second dad surprised us by performing the song ‘Sunrise, Sunset’ from the film, despite not knowing it was from my favourite film.

During our honeymoon in 2004, we saw the Broadway version of Fiddler on the Roof, starring Alfred Molina.

So I’ll go around you as you appear on my screen and ask you to tell us your name and your favourite movie, but you’re not allowed to do what I did, and embellish (!) - just your name and favourite movie.

Introduction

I’m Seiwa Cunningham.
Before I start, I’d like to let you know that if it looks like I’m reading from notes, it’s because I am. Ironically, for someone who works with people living with dementia, I have a bad memory and I lose my words. I’ve also rewritten this presentation so many times that if I didn’t use notes, I would get lost. I’ll try to keep it flowing, though.

David Clegg

I first trained to work with people living with dementia, perhaps 20 years ago. One day of the training was with David Clegg, who is an artist and the founder of The Trebus Project, which is the name he gave to his body of work.

At one point, he became disillusioned with the art scene, so he decided to take a job doing something completely different and became an activity provider in a dementia care home. He ended up recording the residents' stories, as he realised their stories might soon be lost. Eventually, he wrote a book, the title of which he took from this story he tells.

There was a woman called Mrs. Mill who would sit by the locked door to the residential unit because she wanted to get out and make tea for her husband.

To stop her from blocking the door, the staff would tell her that she had a call from her sister. Mrs Mill would walk slowly back to take the call, and by the time she got to the phone, the staff would tell her that her sister had got tired of waiting and hung up. So Mrs. Mill would slowly walk back to the door.

This happened multiple times a day until David decided it was cruel and contrary to care to keep tricking this frail old lady. He sat her down and told her that her husband had been dead for twenty years. She was initially confused, but then visibly relaxed at the idea that her husband wasn't in fact, waiting for her.

David knew that she might forget, so he managed to persuade the staff to tell her the truth in future. The next day, he turns up for work, and on the notice board, there's a message saying "Tell Mrs. Mill her husband's still dead."

Eager beavers

In contrast to David Clegg's story of what seems a rather offhand attitude to people living with dementia, are the earnest looks I get when I run a dementia awareness class for people who have no experience of dementia at all.

There's a real eagerness to learn whatever it is they can do to do right by people living with dementia, almost as if I'm about to tell them how to spin straw into gold. As if people living with dementia are mythical creatures.

Then there are the bodies of research, the papers, the case studies, and numerous books on, covering the subjects I'm tackling here. I personally sometimes find it hard to keep interested when the copy is quite dry and clinical, and (quite rightly) name-checks sources. And there will be a lot more to come.

There's nothing wrong with any of that, but I want to say that nothing I say here is going to be dismissive, or clinical, or dry, or written on tablets of stone.

I'm not presenting this forum under the illusion that I am some sort of guru on dementia, and I don't claim to have all the answers, but I what I do claim is 38 years of facilitating creative workshops, 15 of those focusing specifically on People Living With Dementia, decades of in-depth conversations with carers, alongside 3 years as a trained social carer in Camden and 8 years as a carer for my mum. I claim that, and maybe my perspective will resonate with you, and maybe you might even learn from.

At the end of this hour and a half, you might not walk away with everything you'd hoped to hear, but hopefully, you'll feel inspired to take an action, whatever that might be. I'm desperate for us to all transition from continually discussing dementia to actively engaging in supportive practices that truly make a difference.

I want to express my heartfelt gratitude to Flourishing Lives for their unwavering support over the past year, which has been instrumental in bringing us to this forum today.

The concept for this forum originated from a project I'm developing in collaboration with the Royal Hospital, the home of the Chelsea Pensioners. The project will involve veterans living with dementia who are residents in the hospital's care home. The twist is that we will be inviting residents from a nearby care home to join us.

We'll focus on connecting with and enjoying the beautiful outdoor spaces that can nurture connection and joy. Unfortunately, the project has been postponed until the end of August. The delay is almost par for the course and highlights one of the things to take into account when planning a programme like this: to allow a really long run-up to a project starting.

Today, I want to highlight something really important: the experience of carers for people living with dementia (PLWD). As a carer, whether a professional or family one, it's important to remember that taking care of yourself is not a luxury — it's an absolutely necessary.

So, although I have nothing to report right now on the project, I should be able to give a full report when we meet for part 2 of this forum on September 9th.

Two things inspired this project: the first, is that I passionately believe that People living With Dementia deserve to continue experiencing the things that gave them joy in life, like engaging in activities, taking walks, enjoying pets, visiting galleries, watching beloved movies, tea dances, and continuing to nurture connections with family and friends by visiting them.

The second thing was my involvement in Enliven — ENLIVEN was a 3-year programme running from March 2021 to February 2024, based at the University of Exeter. The primary focus was to enable individuals to maintain their activity levels, independence, and social connections through increased engagement in outdoor activities.

I ran 10 successful workshops at Kew Gardens and the 5 at the National Coal Mining Museum in Wakefield, and they really cemented the benefits of people living with dementia engaging with the outdoors.

So that’s the background behind this forum.

As a freelancer, I often get asked, “So, what do you do?” and I have to admit, it can be a bit tricky to explain! I usually say, “I’m a creative health facilitator,” but then I can see the confused or blank looks.

My work is quite varied! It can be anything from developing an assessment framework for the Mayor’s Dementia-Friendly Venues Charter to making a fun papier-mâché rabbit for an art installation.

Some of you may recognise some of the stories I share, and if you’ve heard them before, I appreciate your patience!

I know it can be hard to step away from that long to-do list, but you truly deserve some time for yourself. It’s crucial not just for your well-being, but for those you care for too. Self-care doesn’t have to mean a weekend at Champneys; it could mean taking 10 minutes every couple of hours or so to have a cup of tea and a doughnut, ordering a takeaway for dinner instead of cooking, and actively savouring that takeaway! You could put your phone on silent and take a long bath while listening to music or reading.

The trick is to consciously experience even these simple things as a treat. By savouring these everyday things as special, hard-earned, deserved, and as essential as the care you're giving to someone else, you will elevate them out of the everyday, and they will feel like genuine self-care.

Work me - slide 1

For the first 23 years of my career, I led creative workshops for all sorts of audiences, from little kids to families in schools and museums. Since 2010, I've focused mainly on running workshops for people living with dementia either on their own or with their carers, and I run workshops for carers on their own too.

Private me - my support system slide 2

You might wonder why my private life is relevant. Well, my background and personal experiences deeply influence what I do at work. When I show up for a session, I bring with me the love, support, and lessons from my family. It all intertwines in a meaningful way!
So when I show up to a session, wherever it may be, I show up with my family:

I show up with the weight of their love, their prayers, their advice, and their lessons. What I do at work happens because of what I've done in my private life

Mum - slide 3

This is my lovely mum, Elizabeth. She had the best smile in the world. In the photo on the left, she was in her early forties and in the photo on the right, she was 91, and this was about 18 months before she died. She had been deafened by the infection that ultimately caused the dementia, so we would write her notes, and she would answer. She's laughing here because she was reading something my son had written. She thought everything he said was hilarious. I saw a letter she'd written to someone in which she said, 'My grandson makes my life worth living.'

Alicia and Daniel - slide 4

This is my adorable granddaughter, who has severe FOMO and is fighting to stay awake in this clip. It really saddens me that my mum never got to meet her great-granddaughter.

This is my son, my only child, whom my mother helped care for about a year. Then she took him to Ghana for a year, allowing me to return to work without childcare worries.

Decades later, my mother returned to live with me, and my son supported me in caring for her. He worked different hours from me, so it meant I could go out to work in the morning, knowing my son was around in case Mum needed anything. By the time I got back home in the late afternoon or early evening, and my son would only just have left for work, so Mum was never on her own for long. My next-door neighbour had a key to my flat, as did an aunt of mine, and I also have a key safe.

Anyway, I really treasure the full-circle moment of my mum caring for her grandson, and then her grandson caring for her.

Family - (behind every great woman, is a great woman?) - slide 5

This photo shows a special moment with my family at my mother’s funeral in 2021. Most of the people in the picture are either my mum’s cousins or my own cousins, who are the children and grandchildren of her three sisters.

When they were younger, many of them lived with one aunt or another. One of my cousins even calls his own mother "auntie" because he doesn't want to differentiate between the relationship he has with his mum and the one he has with his aunties. We really are a close Family! My family sometimes physically show up at my work.

My son often helps out by taking photos at my workshops, meetings, and conferences. He’s fiercely intelligent, and in between snapping pictures, he loves to ask questions and join in on conversations with the participants, which adds a nice touch to the events.

Sometimes, I would take my mum along to my workshops. Since I was working with people living with dementia, it made sense to include her in the process. She became my go-to test subject; if she could tackle a project, I knew others could too! And if she found something tricky, it allowed me to adjust before presenting it to a larger group.

At the end of the day, my family means the world to me. Their support gives me the encouragement I need, and we’re on this journey together!

The point is that without these people, I wouldn’t be able to get out of bed in the morning, so when I show up, they show up with me.
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‘Take A Walk In My Shoes’ part 1 - slide 6

So now that I’ve introduced you to my family, and before we go into the next bit, I’m going to ask you all to do an exercise with me. Close your eyes and really try to tune in to nothing but my voice and my words for the next few seconds.

Breathe in deeply and hold for a count of 5. Now, let that breath out slowly. With your eyes still closed, imagine that you are in bed, either in a deep sleep or trying to get to sleep after having had a bad night.

Now imagine someone coming into your room; they may be a friend, a relative, or someone else. You may not know or remember them. They may be wearing a mask. They shake you and tell you that it’s time for a shower or a wash. And so your day and every other day after that, begins.

Now open your eyes, but hold that last thought.

‘Take A Walk in My Shoes‘ part 2 - slide 7

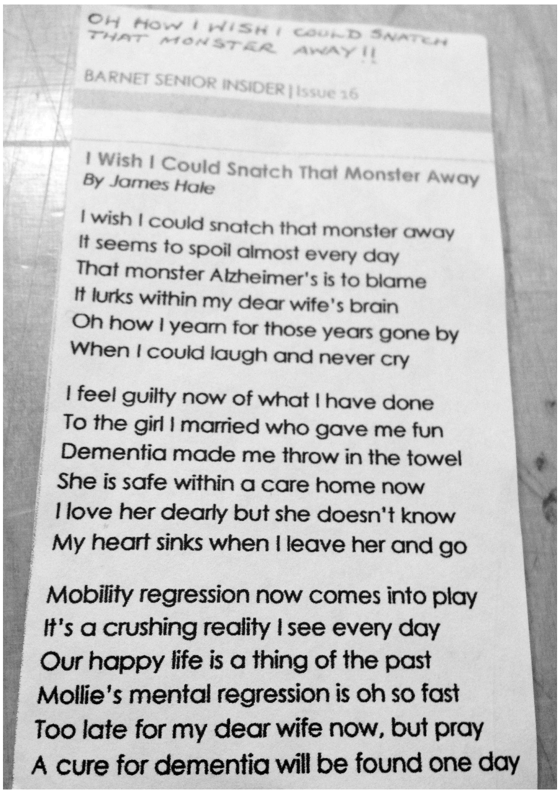
This time, keep your eyes open and see me: Imagine me entering my mum’s room. I know she’s had a shower because in the early hours of every night, I hear her slippers shuffling along the floor as she makes her way to the bathroom. hear her making that peculiar, loud, continuous droning sound she makes 12 hours a day without knowing she’s doing it and that no health professional has been able to explain.

I shake her and tell her it’s time to get dressed in the clothes I left out for her the previous night. And so begins my day. The day could consist of me leaving my mum a cooked lunch in the microwave, going out to run a workshop or caring for someone else’s mum who has a diagnosis of dementia.

I might be taking my mum to her regular check-ups at UCH, because she has a condition I can’t remember the name of, which means she might get cancer. Or I might have hired a car, taken her for a drive, parked outside one of our former homes in South London, and reminisced about living there in the 60s and 60s. Or I could be trying desperately to catch up on sleep, because I’ve spent most of the night trying to persuade my fully dressed mum that the police are NOT asking her to come out, nor are any of the myriad voices threatening to kill her.

I haven’t told you about my key ingredients yet, but if I’m not wearing my Key Ingredients, I am not going to have a good day, and most other carers won’t be having one either. Whether you’re caring for a family member, a service user, or a resident of a care home, it takes both a physical and a mental toll on you.

Molly - slide 8



OH HOW I WISH I COULD SNATCH THAT MONSTER AWAY !!

BARNET SENIOR INSIDER | Issue 16

I Wish I Could Snatch That Monster Away
By James Hale

I wish I could snatch that monster away
It seems to spoil almost every day
That monster Alzheimer's is to blame
It lurks within my dear wife's brain
Oh how I yearn for those years gone by
When I could laugh and never cry

I feel guilty now of what I have done
To the girl I married who gave me fun
Dementia made me throw in the towel
She is safe within a care home now
I love her dearly but she doesn't know
My heart sinks when I leave her and go

Mobility regression now comes into play
It's a crushing reality I see every day
Our happy life is a thing of the past
Mollie's mental regression is oh so fast
Too late for my dear wife now, but pray
A cure for dementia will be found one day

Before we move on and while you're still envisaging that carer, I'd like to show you this poem written by a carer.I used to run workshops for Alzheimers' Society in Mill Hill (I think) and James and Molly were regulars. Molly was very quiet and mostly non-verbal, but she enjoyed trying the different projects.

A few months after those workshops ended, I was at meeting with someone from the Alzheimers' Society, and there was James speaking to her! I asked him how he was and where Molly was and he told me that Molly was now in a care home because she suddenly declined rapidly and he could no longer cope.He added that the pity of it was that he couldn't even really visit her because she had taken to slapping and spitting at him.He showed me this poem he'd written and gave me permission to share it.

Jeopardy

To kick off our discussion properly, how about we play a fun game of Jeopardy? I'm sure many of you know how it works, but just in case you don't, here are the rules: I'll read a statement, and you'll respond with your answer in the form of a question.

For instance, if I say, "This British politician and lawyer has been the Prime Minister of the United Kingdom since 2024 and the Leader of the Labour Party since 2020," you would respond, "Who is Keir Starmer?"

The clues for our game will come from the title of our forum: "An ABC of Creative Dementia Interventions: Agency, Best Practice, and Co-Creation." As we explore these concepts, you'll notice that they often overlap within a single conversation, situation, task, or activity.

If you know the answer, raise your hand - I mean your real hand, not a virtual hand, because it'll be easier to spot - and I'll say your name and ask you for your answer.
Okay, here's the first statement:

What is Agency? - slide 9

Seiwa:
A person's ability to make their own choices, to act independently, and to initiate and control their actions while having a feeling of being in charge of those actions.

Group:
What is Agency?
On the one hand, having a strong sense of agency might motivate a person living with dementia; on the other hand, we recognise that some People Living With Dementia may find it difficult to process choices.

Like children, people living with dementia often have their sense of agency overlooked because we believe they can't make rational decisions, or that their ability to navigate or execute tasks may be compromised, which in turn puts them at risk of harm

When we're thinking about agency, we have to remember that it isn't about taking away dignity or independence; rather, it's about introducing an element of safekeeping and risk assessment. We're called carers for a reason. Also, agency can be 'negotiated'.

1. I know of one carer whose mum had a diagnosis of dementia, but still managed to be independent enough to do her own grocery shopping. Out of the blue, she didn't want to go shopping anymore.

Her daughter finally found out that her mum couldn't cope with money or change any more. The daughter had a word with the shopkeeper, who then began to help her mum with handling her money. So for the moment, her mum can carry on shopping by herself without worrying about getting muddled with money.

She has the agency to go about the activities of daily living up to the point she can manage them, and where she can't, someone steps in to cover that, so that she can retain some independence and her feelings of usefulness.

I've seen this called **Assisted Autonomy**.

When discussing agency, we should acknowledge that it doesn't have to be an event. It doesn't have to be deep and meaningful.

Agency can show up in lots of subtle ways beyond just words! So we need to keep an eye out for the little hints in their tone of voice or facial expressions.

2. While working as a social carer, one of my service users was a lovely 90-year-old lady living with dementia. She got four care visits a day from her carers, including me and a few others. When I would start her personal care, I'd ask if she wanted me to change her. Sometimes she would say, "If you like," but most of the time, she'd say, "No, I'm dry."

She lived with her son, and one day, he approached me a bit upset, saying, “The other carers are not changing my Mum!” When family members say “the other carers,” they’re pretending that they’re not including you, but you know that they are.

Anyway, I explained to him that his mother frequently refused personal care. He told me to just go ahead and change her anyway. I gently let him know that while I might sometimes go against my own mother's wishes for her own good, it wasn’t right for me to force personal care on a service user.

In the end, I found a way to make it work by saying to her, “I’m just going to freshen you up,” which encouraged her to let me proceed. This way, she still had the choice or agency to say no, but by stating my intentions instead of posing a question and giving her the opportunity to say no, we both felt good about the outcome.

3. Yet another time, I set up a colourful still life of fruits and vegetables at a day care centre and invited a group to draw it as best as they could.

One gentleman kept taking an orange out of the bowl, placing it on his paper, then trying to draw around it. I would gently return the orange to the bowl and explain that it needed to stay there.
After a few rounds of this, it hit me: “What am I doing? This is his way of understanding the task, and honestly, it’s not a bad approach at all!” By recognising the person living with dementia’s way of doing things, he showed me a new perspective on how to complete the task.

What is best practice? - slide 10

Seiwa:
A method or technique that has been generally accepted as superior to alternatives, because it tends to produce superior results. This method is appropriate for the individual and makes a positive impact on their lives.

Group:
What is best practice?
In dementia care, best practice focuses on person-centred care. For what I do, best practice means working with People Living With Dementia to maintain their sense of personal identity

while they are engaging in creative and meaningful activities such as art, music, creative writing, dance, drama, or reminiscence. It also means respecting, encouraging, and celebrating how they choose to engage (or not) in an intervention.

For me, it is best practice to make sure that the location of the activity is accessible, Check noise levels, acoustics, light levels, the presence of mirrors and reflective surfaces and so on.

Since less than 7% of our communication is verbal, we need to be aware of both their body language and ours. When speaking to someone with dementia, it is best practice to position yourself at their eye level, as maintaining eye contact is crucial. You need to be close enough to them to engage comfortably, be patient and look interested in what they're saying. Carers have often heard their cared-for's stories a thousand times, and might roll their eyes or try and shut their person up, but as a facilitator, I'm happy to be their new audience.

These points also apply under the 'Take Good Care' section of my Key Ingredients, which I'll talk about later.

What is Co-creation? - slide 11

Seiwa:
Designing with people living with dementia means developing products, services, and interventions with them, rather than for them, ensuring that their needs and preferences are at the forefront. This approach fosters a sense of agency and inclusion, leading to more relevant and effective solutions.

Group:
What is Co-creation? Co-creation can happen at any stage of a project, whether at the beginning, during, or at the end. While not every stakeholder may have an equal stake or say, what is important is the element of collaboration in creating meaningful solutions.

Co-creating / Art - slide 12

With art projects, there are so many directions that it could take us in, and so many ways a project can be co-created.

I’m principally a textile designer, but I dabble in a lot of different craft media. If you're a facilitator or activity provider, it’s possible to stretch your budget and your bank of ideas by taking one thing and reproducing it in different media. For instance, I once felted a giant tulip, then I created a textile tulip out of fabric and embroidery, then I painted a tulip in watercolours, then I created a mosaic tulip on a coaster.
Here’s an example of an intervention you could say I co-created with my mum.

Mum’s ‘private view’ - slide 13

When my mum first came to live with me, I went through a long process of getting her to try things to keep her engaged when I wasn’t at home with her. I tried board games, magazines, books; she used to crochet and knit, so I bought her knitting needles and wool, but she finished that in 3 days and at £67 for wool and a pattern, I knew I couldn’t keep that up.

Eventually, I discovered adult colouring books and to my amazement, she spent the next 7 years filling dozens of these books. She had a great eye for colour and pattern. To keep her encouraged, I photocopied some of her best work, created an artist’s biography for her, then invited friends and family to a ‘private view.’ I put her work up around my living room, and we would have cheese and wine. This bio is from the second ‘private view’ we held. The private views thrilled my mum and created an opportunity for her to socialise with friends and family, all without her leaving the comfort of her chair and footrest.

Co-creating / Music - slide 14

As creative activities go, I often find myself a little envious of musicians. When I invite people to join in an art or craft activity, I hear: “I can’t even draw a straight line!” or “I wasn’t good at art in school.”

It’s like they’re eager to share their hesitations and caveats! *When it comes to music, however, the reaction is very different. Whether it’s joining in with a sing-along to someone strumming on a guitar, or enjoying a piano performance, people naturally start tapping their feet, swaying, clapping, or even get up and dance.There are no caveats or disclaimers, just joyful engagement.*

In some African cultures, there’s a beautiful belief that music is not really written—it already exists in the air around us, just waiting to be heard. So when we pick up an instrument, we are simply accessing this creativity, and the sounds we create are the spirits talking to us. I think they might be on to something. And if the way PLWD respond to music isn't spiritual, I don't know what is.

Ways in which music is intertwined in our lives

- Music is woven into the fabric of our lives in so many ways.
- It becomes a part of our identities, our life stories, and our childhood memories.
- For instance, mothers often use music to calm and entertain their babies.
- Think about how chain gangs used to sing to keep a rhythm while they worked, or how popular singing and dancing competitions light up our TV screens.
- Then there's the background music we hear everywhere, from the national anthem stirring feelings of patriotism to lively football chants that rally the crowds.
- And let's not forget the joy of dementia choirs!

According to Simmons-Stern et al, research suggests that People Living with Dementia remember sung words better than spoken words. (Simmons-Stern et al 2010, Palisson et al 2015).

So this could mean that not only does music help to improve mood, cognition and challenging behaviours in PLWD, but it might be possible to convey information and prompts to People Living With Dementia, including Activities of Daily Living, by using music and lyrics. So, for instance, the situation with the 90-year-old lady I described before, perhaps I could have set the request to perform personal care to the music of 'The Wheels on the Bus Go Round and Round.' It's worth exploring.

I actually know several People Living With Dementia who use singing as a diversionary tactic if they can't follow what is going on, or need time to think before giving an answer to a question.

Defining Creativity - slide 17

As we explore co-creation, it makes sense to talk about creativity, too. For this discussion, I'll explore synonyms of creativity, such as imaginative because 'creative' can also mean thinking outside the box. Some other synonyms are:

Clever

Ingenuous

Inspirational

Inventive

Original

Resourceful

Visionary

So, a creative intervention doesn’t have to mean just the arts, painting, music, theatre, it could mean thinking outside the box. The more ‘outside the box of creativity activities can be made creative. People living with dementia need activities that can help prevent frustration, boredom and challenging behaviours.
Activities don’t only pass the time, but also help the person retain important skills and provide enjoyment and social contact:
Will often compensate for lost abilities
Help the person maintain independence in and around the home
Help maintain skills
Improve self-esteem
Improve the quality of life for the person with dementia, and you will also benefit •
allow the person to express his or her feelings, through art, music, singing and dance •
bring pleasure to both of you as you share these moments together •
provide social contact through social activities and outings,
keeping both of you in touch with family and friends.

Don’t forget to look after yourself too.
Involve other people as much as possible, as that will help you cope.
Don’t feel you have to fill every minute of the day! Quiet times are important too, including sleep.

Now, let’s spark some ideas! Can you think of any creative or unconventional activities that could work well in a care home or places like a museum? And work for either a larger group or just one or two PLWD?
I have some ideas, but before I share them, please put your ideas in the chat, and David, could you please read them out?

Creative (slightly out of the box) interventions to try

1. Mystery shopping adventures
2. Care home residents enjoying a tea dance at another care home
3. Relaxing on a park bench for some people-watching or bird-watching
4. Feeding the ducks together
5. Visiting a reception class or inviting them over to share a fun time
6. Visits from therapy Animals
7. Nature Walk: - Take photos and use our smartphone to show the person living with dementia how technology can help to identify different plants and shrubs together.
8. Reminiscence: Sharing stories, both personal and fictional, can stimulate memory and imagination. s something that some facilitators and a few health care professionals can be dismissive of, or get snooty about, but I think it's because they haven't seen reminiscence done
9. Activities of Daily Living, encouraging independence, cooking, baking, (me and mum)
10. Activities should be appropriate to the person and reflect his or her previous and present interests.
11. Often, activities are best planned for the morning when the person is more likely to have energy for them. Quieter activities are often better in the afternoons and early evenings, when some people with dementia feel restless. Having said that, it can be difficult to help a person living with dementia

Daisy Daisy - slide 15

Ninety year Ninety-year-old Person Living With Dementia playing 'Daisy Daisy' on the piano. She also played it on the accordion.

Music for Life programme - slide 16

On another note, I recently wrapped up a fulfilling role providing training and support for Wigmore Hall’s Music for Life programme, specifically their Monday Afternoons sessions for PLWD.

It’s a heartwarming space, where people diagnosed with young-onset dementia come to enjoy music, whether on their own, with a friend or family member, or a professional carer. I must admit, when I first started this role, I was filled with excitement about what we could create together!

I wasn't quite sure what to expect from the sessions, but I soon became excited about what we could create together. What I discovered was that a strange kind of magic happens.

We gather in a circle, with musicians sitting at different spots among us. One might be playing the flute, another the harp, and yet another the viola.

Right in the centre is a table filled with all sorts of percussion instruments, like maracas, shakers, tambourines, and many more.

After the musicians greet us with some beautiful framing music and a welcome song, we’re invited to pick an instrument from the table to play.

The great thing is, no one is pressured to play if they don’t want to. You can help out with an instrument, or just have one nearby in case you feel inspired to join in later.

The great thing is, no one is pressured to play if they don’t want to. You can help out with an instrument, or just have one nearby in case you feel inspired to join in later.

The musicians might ask someone to provide a note, and the magic begins! With everyone free to make sounds with various instruments, sing, wave their arms, or even dance, we all come together in a wonderful act of co-creation.

None of us really knows where the music will take us, but we enjoy the journey together. We have a PLWD who writes poetry, and he might read one of his poems over the top of the music, or we might turn his poem into lyrics.

Another Person Living With Dementia enjoys drawing mandalas, and when she shares those with us, we find them incredibly inspiring. She also loves playing the drums, so the musician in charge of them knows to give her a chance to play after a while.

One participant loves to dance, while another might walk around the circle chatting with herself or others. Even if what she says isn't always clear, we engage with her in a way that feels right.

Her husband often brings his violin to join the musicians, adding even more joy to our session.

The beauty of agency, with a side helping of co-creation, doesn't have to be mapped out beforehand and written in stone; it can just happen in the moment, and within any creative intervention.

Reminiscence - slide 17

Remembering Yesterday, Caring Today - Reminiscence Sharing stories, both personal and fictional, can stimulate memory and imagination. s something that some facilitators and a few health care professionals can be dismissive of, or get snooty about, but I think it's because they haven't seen reminiscence done the way Pam Schweitzer and her RYCT Programme does it.

RYCT or Remembering Yesterday, Caring Today, is designed to support families living with dementia. People living with dementia and their family carers meet over a number of weeks (from 10 – 12 weeks) to revisit their shared past experience and explore it in a variety of creative ways, including music, drama, art, objects, multi-sensory stimulus and non-verbal communication.

RYCT is an inspiration to family members caring for people with dementia. The programme provides empowerment for the people living with dementia, whose long-term memories have proved more resilient than their relatives dared to believe, and good new working methods for hard-pressed practitioners.

▶ Remembering Yesterday, Caring Today

Key Ingredients

Now I can tell you about my Key Ingredients -
In 2024, Queen Mary University in London ran a research project they called 'Key Ingredients.' They asked 8 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.

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 for times you are engaging with PLWD. Like other dementia-friendly changes you might make to your own home, a care home, or venue, the big plus is that people with other types of neurodiversity could also benefit.

I’ll read out my key ingredients very quickly. They are:

The Welcome - slide 18

This is no.1 on my key ingredients list because in 2024, Sam Curtis of Resonate Arts and I were asked by the GLA to create an assessment framework for cultural venues that had been accredited as dementia-friendly under the Mayor’s Dementia-Friendly Venues Charter. We sent PLWD, some with their carers, some without, to act as mystery shoppers, visiting venues chosen by us that were accredited as dementia-friendly. We asked them to feed their findings back to us.

To our surprise, we found that what made the strongest impression on them was the venues where a member of staff was wearing a dementia friends pin or a sunflower lanyard. That friendly face, wearing a badge that meant they could help if you had a situation, meant a lot to our mystery shoppers. That’s why it’s number one. Whether the PLWD is walking into a day room in a care home or a side room in a community centre, making eye contact, making them feel welcome, making a bit of a fuss, it could set them up for the session, if not the day.

Tea and Biscuits - slide 19

This is self-explanatory and is obviously part of the welcome. The opportunity to take their coats off, sit down, warm up, catch their breath, decompress from the journey to the venue, (whether the journey is from their bedroom to the day room or from their home to the V&A) and to warm their hands on a mug of tea, while surreptitiously running an eye over the others in the room.

Empathy - slide 20

This is about taking time to register that they've taken the trouble and time out of their day to attend your session or workshop, that they are hoping to have a good time and lose themselves for an hour or so. They might have had a bad night's sleep, a bad journey to the venue, or just not be feeling 100%, so showing that empathy helps. Even if some memories are lost, PLWD may still have intuition and remember and recognise emotional cues.
On the other hand, there may be some PLWD who are reluctant to engage. Showing that you understand their hesitancy to join in, whether it's due to a lack of confidence, a language barrier, or not feeling well, may help to break down any barriers to participating. Something as simple as seating them next to a PLWD who is friendly or confident could make the difference.

Connection - slide 21

This is a bit like point 3, except you will be looking specifically to find an area of connection with either the PLWD or their carer or companion. That could be by gently asking questions about their story, discovering that you both have cats, like gardening, both had parents who were bus drivers, or anything that establishes a connection which you can revisit each time you meet. I think what PLWD also value is a bit of emotional connection, a feeling of being valued or even loved.

Take Good Care - slide 22

This is about three things for me. The first is safeguarding, such as knowing your materials and equipment are safe to use, that no one has allergies, phobias, issues with loud noises, trip hazards, no water spilt on the ground, and so on.

You also need to be vigilant and sensitive to issues that might come up as time goes on, for instance a PLWD who might be inappropriate with members of the opposite sex, eats paper (!), tries to drink the water that paintbrushes are washed in, who might try walking out of the room, etc.

For me, it also means this: Article 27 of the Universal Declaration of Human Rights says "everyone has the right to freely participate in the cultural life of the community, to share scientific advances and their benefits, and to get credit for their own work." Creative activities don't just pass the time. They are an important part supporting the cultural rights, human dignity, wellbeing and emotional health of PLWD. That sounds to me like the UN is promoting social prescribing!

It's important to give carers your time and attention too. A lot of family carers are tired and frazzled. Carers have different motives for engaging in creative interventions. Some will take part in activities, not just for the sake of their person cared for, but for themselves too. Other carers will choose an activity that they themselves used to enjoy, because they need to get out of the house for the sake of their own sanity. If they're lucky, their cared-for will enjoy the activity too, and it's a win for everyone.

Some will choose activities that their cared-for might have engaged in before their diagnosis, in the hope that the activity will ignite familiarity or enjoyment. The problem with this is that if a PLWD has lost the ability to engage in an activity they formerly found easy, it can cause distress.

Some carers are so thrilled when their person is engaging in an activity that , for them, it's job done, and they are happy to simply enjoy the pleasure their loved one is getting from Other carers want volunteers or the facilitator of the activity to spend lots of time with their person, so that they, the carer, can get on with enjoying the activity on their own terms, while their person becomes someone else's responsibility for a little while.

It's important to notice that, and to facilitate that if possible. It's a couple of hours of respite for the carers that they will appreciate, and they will think fondly of the facilitator, the activity, or the venue, and return again and again. Like the welcome, people remember how you made them feel, and if you make them feel good, they are more likely to return.

I used to be a Creative Befriender and was once matched with a lovely widow who had been a well-known gallery owner. On the day I was introduced to her in her home, the programme manager kept prompting this lady to show me photo albums of her gallery, exhibitions, newspaper cuttings and so on. The next time I visited her on my own, and asked to see her mementoes. She brought them out, and I began to ask her questions about them. It soon became clear that not only could she not remember much about her former life, she also couldn't really see her own photos and was finding the focus on her former skills distressing.

I’ve seen the same thing happen with PLWD who had told me they used to be seamstresses, but find themselves unable to produce a simple running stitch.

The Process - slide 23

PLWD should never be made to join in, but can be invited to remain at the table or whatever the case may be, observing or perhaps trying their hand at another, simpler or more familiar activity.

During the session, when demonstrating or giving instructions, be sure not to give too many instructions at once, and speak slowly, so that people don’t feel rushed or lost, but can keep up and concentrate.

Remember that for some PLWD, hearing, following, processing and unpacking normal conversation might be difficult; more so instructions for a process they may never have tried or heard of before.

When there are many carers taking part in the session, as a facilitator, you have to create a balance between a pace or style of delivery that makes it easy for the PLWD to follow and a pace that keeps the carer interested. If I happen to be running a session in which the ratio of volunteers and carers to PLWD is one to one, I will often deliver at a faster pace, knowing that the volunteers or carers can take their time repeating the directions to the PLWD.

As far as processes, and as with the example of the orange, if a participant discovers an alternate way to produce an outcome, I will often compliment them and share their technique with the other participants, in order to give them encouragement and a sense of pride.

The Outcome - slide 24

I often say, “There’s what I’d like to happen, and there’s what actually happens.” There’s nothing wrong with having a specific outcome or goal that you’re working towards or that you’d like to achieve. I’ve learnt to keep my itchy, controlling fingers off People Living With Dementia’s work, and leave the work speak for itself.

This photo sums up my idea of a perfect outcome: A smiling face and some wonderful work. This lady took part in the Enliven project at Kew Gardens.

In this session, I took inspiration from the Marianne North Gallery at Kew, mixed that in with a discussion we'd had about Caribbean fruit, and modelled ourselves some colourful specimens.

This Lady was non-verbal, but when we asked her to pose for this picture, she was very happy to. Another lady from her group nudged one of my volunteers and said, "Look at her. I don't know what she's smiling about; she never smiles." This was amazing, unsolicited feedback that made our day!

Often, the piece will have a use such as a drinks coaster, a door sign, or something similar. This is so that their work can be displayed and not shoved into a drawer and forgotten.

It frequently happens that even during the session, the Person Living With Dementia won't remember having made the item. But even if they can't recall the memory, in the moment, we are doing something meaningful together.

When I can, I try to display the artwork or object, so that it's a continual reminder for those people living with dementia who **can** remember, and for those who can't remember, their family members and health professionals will.

I think it is important for people in the PLWD's circle, to be reminded that their person still can create (something from nothing) and that by using creativity, we can cock a snook at the tragedy narrative that is often woven around a diagnosis of dementia.

So those are my Key Ingredients. I psych myself up with my Key Ingredients before I go into a session. Unlike care home activity providers, I don't have to facilitate activities every day, so I think it's easier for me. I imagine (and hope) that there are times they have to put a game face on. We're all human and have bad days and good days.

Key Ingredients are also the outfit I have to wear whenever I'm spending time at a workshop with People Living with Dementia:

I think of it this way: I'm pretty sure that the cast members at the Disney Parks aren't perky 24 hours a day. Walking around in heavy, hot costumes and wigs, smiling and posing for pictures… there's no way they can be that way all the time. I imagine they have to psych themselves up before the gates are opened to millions of visitors.

You might have heard the story by Amy Greene, the wife of Marilyn's personal photographer, Milton Greene.

She and Marilyn were walking down Broadway once, when Marilyn turned to her and said, 'Do you want to see me become her?' Amy didn't know what Marilyn meant, but she just said 'Yes'.

She says she can't explain what Marilyn did because it was so very subtle, but she turned something on within herself that was almost like magic. And suddenly, cars were slowing, and people were turning their heads and stopping to stare. They were recognising that this was Marilyn Monroe as if she pulled off a mask or something, even though a second ago nobody noticed her. Amy said she had never seen anything like it before."

I think of my Key Ingredients like that sometimes, especially on days when I might not be 100 per cent: it's a switch I turn on in my head.

End