

Creative Age Project for People with Dementia and their Carers, Cheltenham

A partnership project between Bethesda Methodist Church, *Open Arms Artists' Collective* and Managing Memory Together (part of Gloucestershire Health & Care NHS Foundation Trust)

The Story of *Creative Age* since March 2020, by Lisa Harrison, *Open Arms* artist

Project Background

Creative Age is an arts-based, social community project for people living with dementia and their carers who still live independently. It has been running since May 2018 out of Bethesda Methodist Church in Cheltenham and has been funded by *Thriving Communities* Gloucestershire County Council and Bethesda, with a small start-up grant from The Barnwood Trust. Referrals come mainly via our contacts at Managing Memory Together, Alzheimers Society Memory Cafés and Age UK. The *Creative Age* core team comprises 2 lead co-ordinators (one *Open Arms* artist and Bethesda's Lay Worker), 2 *Open Arms* artists and 3 church volunteers.

Participants take part in focused creative group sessions facilitated by experienced artists, exploring imaginatively with collective story-making, seated movement, dance, music, visual stimuli and poetry, with content driven by the participants' interests. Creative sessions are followed by socialising over tea and cake, hosted and coordinated by Bethesda Church and committed volunteers (who also support the artist-led sessions).

Creative Age was set up to enrich peoples' lives, reduce isolation, enable participants to engage imaginatively and socially, build their confidence and improve their wellbeing. Since Covid-19 we have had to re-think fundamentally how we deliver our project. Our challenge: how to work towards our original aims without regular face-to-face meetings as a group?

Lockdown 1

We started by making many phone calls, checking that people were safe, ok, making sure they had what they needed, and if not, running errands for them. At the beginning of lockdown people seemed remarkably resilient. Our phone calls were greatly appreciated but soon a pattern established itself: we always talked to carers and rarely to the people with dementia.

Carers were apologetic for the same conversation they offered each week, repeating that their partners/relatives living with dementia seemed to be deteriorating more rapidly as a result of lockdown. Without the regular stimulation outside their homes from various activities they'd been involved in before coronavirus, the impact of lockdown on both carers and their partners/relatives with dementia was considerable.

As lockdown stretched out in front us, people struggled more with motivation, depression, frustration, confusion and finding positive things to engage with in their homes. This spurred our driving desire to provide opportunities for *Creative Age* members to interact with each other and well as input fresh stimulation into their lives.

Sustaining a sense of community

Members of the group were connecting with us but not with each other. This, and our lack of access specifically to the people with dementia, caused us increasing concern. To address these things, we:

- set up carers' WhatsApp groups and taught them how to make video calls
- helped people download the Zoom App so that we could run creative Zoom sessions for the people living with dementia

Not everyone had access to the internet, a computer or a digital device and so they couldn't join the Zoom sessions or WhatsApp calls. To us it was paramount to keep the *Creative Age* community intact and not exclude anyone, but there was no 'one-size fits all'. So we decided to start writing a newsletter as well, to reach and include everyone.

The Newsletter

Written by *Open Arms*, the newsletters have been very popular indeed, opening up a whole new dimension of our project. Descriptions of people's lives during the pandemic have been shared, as well as poems, biographical stories, personal photographs and letters. Some newsletters have a theme running through them – such as travel, poetry, the seasons. What we know about each other as a community has deepened significantly through the newsletter – more so, probably, than it would have done without Covid-19.

The participants' desire to contribute to the newsletter has been a clear demonstration of their collective need to nurture and safeguard a sense of 'belonging' and to maintain contact with others they miss seeing. Everyone is 'visible' in the newsletter. "This group gives me hope," said one participant. People send us things to print, including photographs of what they've been up to, to help motivate each other to stay creative.

A group member said in Lockdown 1:

"Another great newsletter. You are amazing. I wanted to let you know that our WhatsApp group had a video call for a whole hour together last week! It was wonderful. I am so looking forward to Thursday's creative session on Zoom. Going on Zoom today for the first time has made my week! I am learning so much about technology. Thanks so much for all you are doing to keep us together. For me it is a lifesaver."

Creative explorations, online and via telephone

Between March and July, landline and mobile calls, WhatsApp, email, Zoom and newsletters were our means of continuing to deliver our project. In our online group sessions, led by *Open Arms* artists and supported by the rest of the team, we have experimented with the following:

- Collective story-making
- Poetry recitals
- Collective poem-making
- Seated movement
- Singing
- Interpretative dance
- Group socialising

Quickly it became very clear that most participants with dementia struggled with group sessions using Zoom. Many found interaction with the screen confusing or disturbing, (“who are all these strangers in my home?”), or their device or their internet connection prevented easy engagement. People with significant hearing impairments had the biggest challenge to stay connected with the group.

So some were given a mix of 1-2-1 and group Zoom sessions, providing them with extra support to feel ‘at ease’ with the new medium; others could only engage with 1-2-1 video sessions. Those who were unable to participate online would take part in sessions over the phone. We’d always attempt to engage the imagination - playing music over the phone, singing together, or doing imaginative story-making...

Reaching those with no internet, those with hearing impairments, and those who find online sessions distressing

Despite tailoring *Creative Age* for each individual in our group, there were still some people we struggled to engage satisfactorily in meaningful interactions. We realised that 3D ‘in-the-flesh’ meetings were vital for those people to make any valuable, real difference.

So after securing some additional funding from Cheltenham Borough Council and spending hours (upon hours!) doing detailed risk assessments, in August and September we went into people’s gardens to be creative with them there. As artists we worked in pairs. We had a glorious time.



Resuming indoor sessions in the Autumn

Buoyed up by the success of the gardens work, and more confident about working in Covid-secure ways, we set about planning indoor sessions at Bethesda. More detailed risk assessments happened with a total rethink of how sessions would need to be run physically and artistically in order to be safe. Our wonderful volunteers were trained up. The new

conditions for participants in *Creative Age* were posted out, to be read and agreed to before people signed up. We also recruited a whole new group and were about to start when Lockdown 2 was announced. Indoor sessions had to be abandoned.

Lockdown 2

Feelings of isolation, hopelessness and depression immediately soared amongst our group members. In response, *Open Arms* artists swiftly put together a programme of online group sessions - singing, movement, dance, poetry...*and* this time also 'carers-only' and group crafting sessions. The new sessions proved very popular indeed. 1-2-1 Zoom and phone sessions with a story-making bias continued with the people who couldn't engage in online group work. Material was gathered for the newsletter this way.

Thank goodness for the postal service! Crafting boxes and newsletters were received with real joy and gratitude. In December we sent out a colourful Christmas collage from photos of treasured objects that carers had sent in to us. These plus a Christmas-themed newsletter provided some solace at a time when most were low and desperately missing their families.

Comments from one participant:

"This year the Covid pandemic has impacted seriously on mental health. I have no doubt that without the support of the CA team I would not have survived mentally. The CA team kept us all motivated. They kept in contact, sent us newsletters, organised different activities – singing, dancing, exercising, crafting - all manner of ways and ideas to give us inspiration and hope. They are such a dedicated and inspiring team. We owe them much."

Reflections at the end of 2020

All participants of *Creative Age* were very appreciative of our efforts to keep the project going through such testing times. Our love for each individual in the group has deepened, and the CA community is still intact. Covid-19 has forced us to think outside the box, to adapt and develop our practise, to explore and discover. However, the pandemic continues to present huge challenges for the artists around the quality and depth of experience for participants in creative sessions. The restrictive conditions have impacted greatly on the flow and energy of sessions, on the depth of interaction, creative stimulation and imaginative involvement. Pre- and post-Covid comparisons may well be unhelpful. Whilst we remain committed to exploring and improving new ways of working, it's still hard at times to put to one side what we know to be true: meeting together 'in the flesh,' quite simply, will always work best for CA.



Windchime and lanterns made in our online crafting sessions

Lockdown 3, January 2021

We are now in Lockdown 3 and people in our group are receiving their vaccinations. Just as hope has become real for our participants, it is now that we as a team are struggling most with motivation to keep driving our project forwards. Last year two of our participants died from coronavirus, two are now living in care homes, two had to spend a protracted period of time in hospital receiving specialist dementia care and one of our key volunteers has dropped out – we hope temporarily - due to her struggles with online sessions. This has impacted on us all.

We are a small team, and along with thousands of others, we are flagging. Thankful for technology and all it has enabled, we're phone-, Zoom- and compromise-weary. And there's still much uncertainty about the virus, our collective safety, when we will be vaccinated...

We know there are many people out there who would benefit from being part of *Creative Age* and we are now prioritising finding those people, particularly those harder to reach. Recruitment has always been one of our biggest challenges, and with current restrictions in place, it will be even trickier. Grateful for continued support from *Thriving Communities* for 2021, we also need additional funding which we anticipate may now be harder to find.

Going forwards

Now is the time we really need support to find the new people, charities and organisations who can help us, and to find the new recruits and the motivation to keep going. We want to collaborate with CCGs, social prescribers, artists, individual practitioners and any organisations working in public health and the voluntary sector with groups similar to ours. If you are one of these, please call us. We'd love to talk.



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