'View from a Window' An Artist in a Pandemic 2 A reflective essay by Nicky Bellenger

"This has really picked me back up" L, participant

When Covid hit, Arts Derbyshire's successful programme of dementia-friendly film screenings, Matinée, had to be put on hold.

Programmes like Matinée become much-needed social events for people living with dementia and their carers; places to connect with others and to momentarily escape the everyday challenges that dementia can bring. The pandemic cut off those connections, particularly for people without access to technology, or without friends and loved ones nearby, causing a large number of people to become isolated in their own homes; depriving them of cultural and social interaction.



Chesterfield Matinée film screening Photograph by Frances Watt

Arts Derbyshire had to postpone all dementia-friendly film screenings, so in June 2020 they launched 'Matinée Outreach'; a project that would connect isolated adults living with dementia with artists via telephone calls and activities sent in the post. I was elated when I was selected to work on the project. It felt good to be part of a creative solution to easing social isolation for those who needed it the most.

The brief from Arts Derbyshire was open and allowed us, as artists, to work creatively with people using art forms of our choice. I had proposed sending person-centred creative writing activities in the post, that would be co-created with participants via the phone calls, responding to the interests and needs of each participant. But regardless of the art forms that we were using, there were some universal practical challenges that we needed to prepare for from the outset. What if someone forgets who we are each time we call? How would we work with someone with verbal communication challenges, who would normally

benefit from body language, facial expressions, and visual aids? What if we are unable to get hold of someone who lives alone, and we are concerned about their safety?

Alongside the participants and their families and carers, we found ways to overcome challenges. The connections made over the phone became truly meaningful, and even if someone couldn't remember my name, most people seemed to remember that they trusted me and enjoyed talking to me. I also posted visual aids to participants, e.g. a photograph of me and an introductory letter, explaining the project and how the phone calls will work. The mix of communication via phone calls and post seemed to work well for most people, and we also supported a couple of participants to use Zoom. People were referred to the project via family, health care professionals e.g. Social Prescribing Link Workers, or agencies and charities, such as the Alzheimer's Society, ensuring we had another point of contact should we have any concerns regarding the participant's safety or wellbeing.

When we started the project, we had no idea how long the pandemic would last. The original brief was to work with individuals over 8 'sessions', and we spoke of the potential for a final, celebratory event or exhibition of some kind, in person. But as the pandemic continued, we realised that the project needed to continue remotely and that 8 sessions wasn't enough. We were coming into contact with people whose dementia was progressing more rapidly than anticipated; carers who were at breaking point; families who had only just received a diagnosis and were receiving little support; and people who were feeling low, craving contact and something to stimulate them. And so people's time on the project was extended, with end dates often left open, due to the unpredictability of the pandemic. We worked with some people for as long as 6-8 months.

'M said she wasn't good today - started by speaking about being told she had dementia, not being able to drive, friends and children not visiting or calling her. I have a feeling this may always be the underlying thing she needs to talk about.' NB's project diary

'She said "I used to be a beautiful writer, now I can't string a sentence together". I think with some gentle encouragement she will be able to write something amazing. At the end of the call she said "please don't give up on me". The phone calls feel so needed.'

NB's project diary

This also changed my creative process. I had planned to get to know each person's interests and needs before designing the activities, but my original intention was to send a set number of activities to each person. As our time with participants extended from weeks to months, this way of working didn't feel sustainable for me, particularly when working with 4 or 5 participants at a time. As a result, the way I worked with each participant depended entirely on what was discussed in the first few phone calls. Early conversations often centred around people's wellbeing and most participants seemed comfortable, perhaps even relieved, to talk about their dementia. How were they coping with the pandemic? How was dementia affecting them? How could creativity help them? They had selected 'creative writing' as the activity they wanted to take part in when signing up to the project, so we then spoke about things they have written previously (from shopping lists to short stories), favourite writers, other ways they are creative, and how much they would like to be challenged. From these early conversations came individual plans for personalised projects. Two participants had already written lots of poetry, and so we decided to record them reading their poems, via Zoom. These videos are now on <u>Arts Derbyshire's YouTube channel</u>, with their permission.



A screenshot of Giulia Artuso's video 'Happy Thoughts', from Arts Derbyshire's YouTube channel

Another participant enjoyed describing the ever-changing view from his window over the phone, as well as the photographs on his wall from his travels, and so we documented these conversations and turned them into a poem. I would send draft copies in the post, for him to edit with me over the phone each time we spoke.

I'm looking at an expanse of beach in Brazil. Bahia. The Atlantic lapping.

I'm looking at blue skies. I'm looking at dogs running across the park. I'm looking at a cyclist. He's collapsed!

There's always something to watch if you look.

(From I Wandered Lucky as a Cloud, Tony Hayes)

Another participant didn't want to write things down but was an exceptional storyteller, often recalling memories from her childhood in impressive detail over hour-long phone calls. Instead of sending activities to her, I sent her small items relating to her stories, to help inspire our next conversation, and with her permission I wrote and framed a poem for her, as a final gift, capturing the many wonderful tales she had shared with me:

if our calls were a library, you would find me on a comfy chair surrounded by books, piling happily at my feet, taking pleasure in losing track of time,

(From Poem for J, Nicky Bellenger)

Another participant wasn't confident in her creative abilities, partly due to the impact dementia was having and a worsening visual impairment, but she loved talking on the phone. With the support of her daughter I discovered she used to write beautiful letters in calligraphy, and so I created large print, laminated calligraphy templates which could be written on and rubbed out time and time again with board pens.

Laughter Garden ave Sunshirve Smile owers

Photograph of participants' calligraphy work

Because of the long-term, 1-1 nature of the work, it was hard not to form personal connections with the people I spoke to; we were living through a constantly changing and unsettling global pandemic together. People's voices were entering my home; the place I was spending all my time throughout the lockdowns. We shared views out of our windows, ideas of how to 'keep busy', and participants asked *me* how I was feeling, even when things seemed unimaginably difficult for them. The art that we created together was born out of weeks of creative, meaningful conversations. "How are you today?" didn't need to be responded to with the instinctive "fine thanks, how are you?". We tuned into complex feelings and emotions, and explored whatever each person wanted to explore creatively in that moment. Together, we found ways of expressing joy, grief, fear, confusion, love, hope... through poetry, short stories, and even a one-woman play.

But the biggest challenge, that I hadn't prepared myself for, was how to say goodbye to people.

As the pandemic continued, so did the requests for people to join. Arts Derbyshire extended the project and took on another artist to meet the additional demand. We started to discuss how best to manage endings. Not only was it important to prepare participants for when their time on the project would come to an end, we also needed to prepare ourselves. This was sometimes made more challenging when participants' short-term memory loss caused them to forget previous conversations, meaning even if we had tried to prepare them for the final phone call weeks in advance, it sometimes still came as a surprise.

Those final phone calls were never easy for me. Saying goodbye to people I hadn't met face to face but had spoken to frequently over a period of months was sometimes painful. Perhaps it would have been easier if things had been 'fixed'... if the pandemic had ended, or if people's dementia had got better; but of course, neither of those were the case. That made those endings even more difficult for me. I like to help to make things better for people, not to

step away when things are going to get harder for them.

'Final call with C today. We reflected on our time working together and C said "Thank you for being so caring". When I asked what she's enjoyed the most about the project she said "I've really enjoyed talking to you". I will genuinely miss our calls.' NB project diary

'I tried to keep it upbeat, but J told me she is sad it has come to an end as no one else calls her. I told her about other companion calls available, including from the <u>Alzheimer's Society</u>, and she would really like to know more about that... We reflected on what we have both got out of the project... I told J that our chats have cheered me up on difficult days through the winter and that I have loved hearing all of her wonderful stories... As the call was coming to an end J said "I've loved our phone calls. Thank you for all you've done for me".' NB project diary

These feelings were complex. As an artist, I am drawn to projects that I care deeply about, often due to connections with my personal life. Working with participants remotely during the pandemic made the work feel even closer to home, and harder to detach myself from. There wasn't a journey home after a workshop to help to create a healthy distance from the work, or the opportunity to take myself to a café to have some time to reflect, as I used to enjoy doing.

Regular debriefs with the team reminded me that I wasn't working alone though, and encouraged me to take a step away from the work when I needed to. Derbyshire County Council Public Health, project funders and supporters, acknowledged the challenges faced by employees and volunteers from across the VCSE sector at this time by offering a programme called 'Help the Helpers' - a range of free services with a Public Health Wellbeing Counsellor. Through this brilliant, and much needed, programme I was able to access free online art therapy sessions after the project had come to an end, which really helped me to acknowledge and process the complex emotions that surfaced as a result of the work.

I feel very fortunate to have worked on Matinée Outreach. The pandemic was a dark and difficult time, but the light to come from it was having the space to gently figure out new ways of working creatively with those who are most isolated in our communities. Long-term, 1-1 creative work, that is genuinely person-centred and co-created, is sadly rare to find. It's expensive, hard to sustain and takes a lot of delicate planning and care. It can also be emotionally exhausting for the artist. But I hope we can hold on to the lessons learned from this time, and keep reaching out to those who are unable to attend our theatres, museums, libraries, community centres. Because with the right support in place, this way of working can be the most rewarding and life changing experience, for both participant and artist. It certainly was for me.

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