

Arts Council of Northern Ireland

# Stories from the Inside

Isolation, loneliness, and the arts,  
in residential care during the COVID-19  
pandemic.

## EXECUTIVE SUMMARY

June 2021



## Executive Summary

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### **Stories from the inside: Isolation, loneliness, and the arts, in residential care during the COVID-19 pandemic.**

A report prepared by Dr Una Lynch for the Arts Council of Northern Ireland

Full report available here: <http://www.artscouncil-ni.org/images/uploads/publications-documents/ACNI-Stories-from-the-Inside-Final-Full-Report.pdf>

The evidence base is clear: social isolation is associated with higher rates of all-cause mortality (Holt-Lundstad, 2018). In recent years, government bodies and other agencies have been working to find ways to combat social isolation and the feelings of loneliness that can be associated with it. The Arts Council of Northern Ireland (ACNI) has been at the vanguard of this movement. Last year, together with its partners the Baring Foundation and the Public Health Agency, through Arts and Older People (AOP), ACNI was set to embark on a radical and exciting programme of work. The goal was to make the arts accessible to people living in residential care. The emergence of the COVID-19 delayed that work. As Northern Ireland (NI) enters the recovery phase of the pandemic, the AOP programme is well placed to galvanise that endeavour.

In preparation for this important work, ACNI commissioned an exploratory study to assess what role the arts can play in supporting the mental health and wellbeing of care home residents and people with dementia. The study identified six themes: (1) isolation and loneliness, (2) environment, (3) feeling connected, (4) fear, (5) dementia, and (6) the arts.

Drawing on interviews with 12 participants, *Stories from the Inside* shines a light on the reality of life for the men and women living and working in our residential care settings through the pandemic. The reality is stark: people restricted to seeing a parent or spouse through windows; interactions mediated through face masks, visors, aprons, and gloves; health care workers emotional and exhausted from caring for people with dementia; residents who through isolation and loneliness simply lost the will to live.

There were also glimmers of light. Images of smiles, laughter, and kindness; images that were frequently associated with and mediated by the arts. The community care assistant who spontaneously sings during visits, triggering conversations, reminiscence, and laughter. The bespoke DVD of old-time music that had a lady singing, after months of being mute. The musician who in his final days was surrounded by the classical music that had been his life. The lively and bawdy musical theatre performances in car parks of residential homes in East Belfast that got people laughing, singing, and dancing.

This study reveals the pivotal role that environmental factors have on supporting social contact and promoting dignity. Residents living in ground floor rooms were in the enviable position of having ready access to a window through which family could wave and say hello. The use of Perspex screens, although useful in the outside world, are inappropriate in settings with people who live with dementia and evidently caused distress for residents and their families. The importance of outdoor areas and having sunrooms, conservatories or patio doors which enabled residents to access arts performance is evident. The Irish climate means that such activities are always weather dependent. The public health measures of social distancing and ventilation are likely to continue for some years. It is therefore of utmost importance that consideration is given to how environment promotes residents' rights to engage with other people and with the arts. Environmental factors are not always about major redesign but are sometimes due to lack of training, awareness, or empathy. The poignant image of an 80-year-old woman left isolated and bereft of any external stimulus in a major teaching hospital is impossible to ignore. All that it took to remedy the situation and enhance the lady's sense of wellbeing was the simple act of placing a chair in a position that gave a view out of the room.

The importance of seeing the person, knowing their life stories and their interests to promote dignity is emphasised throughout this study. A son was able to provide the nurse caring for his father with a vital nugget of information: *"turned out he was a very good musician, he had performed in the Ulster Hall."* As a result, the gentleman's final days were enriched by the classical music that had been such a great part of his life. Such experiences illustrate why life story work should be made an integral part of care plans.

Knowledge and understanding of dementia and skilled staff are crucial in infection control. In addition, in settings where staff have poor understanding of dementia there is an increased likelihood of safeguarding issues and overmedication (Suárez-González, 2020). The need for capacity development and training with regards to dementia awareness was evident. The care workers talked with great empathy about the difficulties that they experienced trying to care for people with dementia. It is to their great credit that they frequently turned intuitively to the arts to help soothe an agitated resident or to keep them occupied during unending periods of isolation. The incidence and prevalence of dementia in NI is increasing steadily. If these people are to achieve their full potential and live with dignity, investment in specialist dementia training for health and care workers is essential.

It was evident that where hitherto there had been some focus on arts-based activity, this had all but disappeared during the pandemic. Activity co-ordinators were either redeployed into the core care team to help deliver hands-on care, or they were stretched to the point that one may question the value of their work. One person working with 30 or 40 residents is unrealistic, when each resident is in solitary isolation, and many have dementia. It is without dispute that staffing levels in residential care have at times been critically low during the past year (NIA, 2021). Ironically during the COVID-19 pandemic the artistic community was amongst the worst hit business sector in NI. Despite innovation and movement to online and

outdoors performance, many artists found themselves unemployed and struggling financially. With a little vision and moral leadership from policy makers and regulation bodies, the arts community could be harnessed to help support staff and people living in residential care. This is a win-win situation which would protect the rights of residents, enhance the capacity within the care environment to enable people to live and work with dignity, and give a much-needed boost to the local economy.

During the past year, artists have harnessed the power of technology to make their craft accessible. Funding from the AOP has made it possible for artists to deliver dynamic and exciting arts-based initiatives for carers, those living with dementia and other isolated older people. Storytelling, singing, visual arts and musical performances are some of the programmes which are currently available. DementiaNI members are participating in these initiatives. A small number of residential care settings have partnered with artists to make the programmes accessible to their residents. The success of these initiatives challenges stereotypical and prejudiced notions about people with dementia and their capabilities.

Although slow to get off the ground, the care partners initiative provides a powerful opportunity to galvanise access to the arts within residential care. Investment in education about the benefits of the arts in promoting health and wellbeing for family members, care workers and others involved in care of older people could quickly and radically change the culture of care provision. The roll out of the COVID-19 vaccination programme and relaxation of some public health measures means that demand for the care partners initiative is likely to increase.

Reunification of residents with their families will be emotional and may be upsetting. It is highly likely that after extended periods in isolation some residents will not recognise their spouse, children, siblings, or friends. Lack of social engagement and cognitive stimulation will inevitably result in a diminution in physical, cognitive, and emotional capacity. The arts could go a long way in helping to mediate these initial encounters and in recuperation of the care environment.

This study focused primarily on the experience of people living in residential care. The fact that most older people and people with dementia live in the community, and in their own home, was also evident in interviews. The needs of this population should not be ignored. Action is needed to counteract the impact that extended periods of isolation and relative immobility has had on their health and wellbeing.

COVID-19 safety measures and ethical issues meant that it was neither possible to visit residential care settings nor interview people who have dementia. The arts provide a powerful and gentle vehicle to explore and document the personal experiences of residents, their families and residential care workers; all of whom have experienced trauma and loss throughout the pandemic. Learning from this work will help inform and shape future residential services in a way that promotes social inclusion and dignity for all.

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