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


The Arts Council of Northern Ireland (ACNI)
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# Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Introduction</td>
<td>1</td>
</tr>
<tr>
<td>2. Background</td>
<td>3</td>
</tr>
<tr>
<td>Figure (1)</td>
<td>4</td>
</tr>
<tr>
<td>3. Aim and Objectives</td>
<td>6</td>
</tr>
<tr>
<td>3.1 Aim</td>
<td>6</td>
</tr>
<tr>
<td>3.2 Objectives</td>
<td>6</td>
</tr>
<tr>
<td>4. Methodology</td>
<td>7</td>
</tr>
<tr>
<td>Figure (2)</td>
<td>7</td>
</tr>
<tr>
<td>5. Findings</td>
<td>8</td>
</tr>
<tr>
<td>5.1 Isolation and loneliness</td>
<td>9</td>
</tr>
<tr>
<td>5.2 Environment</td>
<td>16</td>
</tr>
<tr>
<td>5.2.1 Dignity</td>
<td>16</td>
</tr>
<tr>
<td>5.2.2 Death and dying</td>
<td>20</td>
</tr>
<tr>
<td>5.2.3 COVID-19 Safety Measures</td>
<td>21</td>
</tr>
<tr>
<td>5.2.4 Design</td>
<td>23</td>
</tr>
<tr>
<td>5.2.5 Location</td>
<td>24</td>
</tr>
<tr>
<td>5.2.6 Digital divide</td>
<td>25</td>
</tr>
<tr>
<td>5.3 Feeling connected</td>
<td>27</td>
</tr>
<tr>
<td>5.4 Fear</td>
<td>30</td>
</tr>
<tr>
<td>5.5 Dementia</td>
<td>32</td>
</tr>
<tr>
<td>5.6 The Arts</td>
<td>33</td>
</tr>
<tr>
<td>5.6.1 The importance of the arts</td>
<td>33</td>
</tr>
<tr>
<td>5.6.2 Activity co-ordinator</td>
<td>37</td>
</tr>
<tr>
<td>5.6.3 Artists</td>
<td>39</td>
</tr>
<tr>
<td>6. Discussion</td>
<td>41</td>
</tr>
<tr>
<td>7. Recommendations</td>
<td>45</td>
</tr>
<tr>
<td>References</td>
<td>47</td>
</tr>
</tbody>
</table>
1. Introduction

‘Recovery’ is the word used to describe the next challenge for life lived during the coronavirus pandemic. As the Northern Ireland (NI) community starts to reopen, the residential care sector is taking tentative first steps towards recovery from the onslaught that it has endured for over a year. The loosening of restrictions and reopening of society presents a strong opportunity for the Arts Council of Northern Ireland (ACNI) to influence, shape and contribute to the rebuilding process.

This study is located within the context of the ACNI’s flagship Arts and Older People (AOP) programme. In its twelfth year the AOP is focused on the promotion of social justice and inclusion for older people. The programme recognises the inherent rights of older people to engage with the arts. It also recognises and values the arts as a vehicle to promote health and alleviate the social isolation and loneliness that is all too often experienced by older people. Reflective of its commitment to equity and social justice the AOP has evolved to place increasingly greater emphasis on people affected by dementia. Last year (2020) was to mark the beginning of a new phase in the AOP. Work would see a focus primarily on people affected by dementia and would be mostly located in residential and nursing home settings. The COVID-19 pandemic rendered this endeavour challenging and at times all nigh impossible.

It is against the backdrop of reopening of the residential sector that the ACNI has commissioned this study. The goal has been to learn from the experience of the past year within residential care, how people with dementia have been affected and how the arts have been used to alleviate isolation and loneliness and promote dignity. This work has served to identify how the Arts and Older People programme (AOP) might contribute to the recovery process.

“Absolute loneliness and despair. Nobody, nobody understands. There was nobody listening. Nobody cared. I could not say anything joyful about this last 11 months, it has been horrendous. This has been the most painful experience that I have had. Of separation from a mom who is 91. I'm 63 and I've been a part of her life all of my life to suddenly be removed from that is just cruel.”

(Family Carer 1, February 2021)

The pain, anguish and isolation expressed above are a by-product of public health measures taken over the past year to protect people living in residential care from the coronavirus. In February 2020, the first case of COVID-19 was
detected in Northern Ireland (NI). Less than three weeks later, on March 19th, the first death was reported. NI went into lockdown on March 23rd. In 2020 the people of NI and throughout the world have seen their lives changed in myriad ways. A new lexicon comprising social distancing, quarantining and self-isolation has become part of everyday parlance. Life without hairdressers, shops, restaurant and visiting friends was replaced by a life where home schooling, working from home and wearing of face coverings became the new normal.

COVID-19 can affect anyone, but in the early days of the pandemic it quickly became apparent that people aged over 80 years were at higher risk of serious illness and death. Older people were advised to stay at home and not let family or friends inside. Residential homes closed their doors, and all visits were stopped. Living in tightly enforced seclusion people in residential settings have been largely invisible throughout the past year. Despite these measures people living in residential care have dominated the COVID-19 mortality statistics. The NI Statistics and Research Agency (NISRA) has registered 1,006 COVID-19 related deaths amongst care home residents between March 19th, 2020 and 26th March, 2021.

The global pandemic triggered sudden and brutal changes in policy the antithesis of everything that the ACNI and the AOP have been working towards. People living in residential care had the element of choice taken away from them as facilities closed their doors to everyone but staff. The people behind these decisions were in an invidious position. COVID-19 is a formidable foe. The number of asymptomatic cases means that COVID-19 is not always visible, and people are infectious for 48 hours before symptoms present. COVID-19 thrives when people are near each other. It seizes on the opportunity of weakened immune systems and vulnerabilities to cause serious illness, and all too often death. Residential care settings are the perfect environment for COVID-19 to cause maximum damage. This study was not about the disease, rather it was an attempt to capture the experiences of people who have lived inside residential care settings during the past year. People for whom the freedom to choose to follow the rule was taken away and for whom the lockdown coping mechanisms— walking, baking, learning a new skill —used by those of us on the outside were rarely, if ever, an option.

The study draws on semi-structured interviews with older people, family members, carers working in residential care settings and artists. The findings are at time stark and all interviewees are candid in describing the reality of

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isolation in residential settings. The arts are shown to be powerful in helping people to cope, but access to the arts is revealed to be scant and sporadic. The report concludes with recommendations including: a holistic approach to health and social care governance, which recognises that health is more than the absence of disease; capacity development of care workers with regards to their understanding of dementia; integration of arts-based interventions into individual care plans for residents; a focus on environmental factors including design, use of technology, and the promotion of dignity.

2. Background
“Preventing loneliness in institutionalized persons is at least as important as helping them with personal hygiene. This is especially important during the COVID-19 pandemic when residents must be protected from contact with other individuals to reduce the risk of infection.” (Simard and Volicer, 2020)

The ACNI’s strategic framework (2019-2024) was developed through extensive consultation with key stakeholders and the work over the next three years is guided by shared vision that:

“Celebrates arts and creativity.
Links us to a shared heritage of ideas, words, images and sound.
Helps us to be connected, confident and outward looking.”

For over a decade the ACNI has worked to improve access to the Arts for older people across NI. Together with the Baring Foundation and the Public Health Agency the ACNI’s Arts and Older People programme (AOP) has shone a light on the deleterious effects of social isolation on health and wellbeing and championed the benefits of the arts in promoting inclusion and alleviating loneliness. In 2019/20 the organisations core funded by the ACNI delivered “more than 700 activities in care home settings across Northern Ireland.” (ACNI annual funding survey).

The coronavirus has presented invidious choices for older people, policy makers and providers of care. Age is a major risk factor in developing complications and serious illness from COVID-19 infection. Social distancing and isolation have been vital elements of the public health response to COVID-19. The negative impact of these measures on physical, cognitive, and emotional health and wellbeing is well recognised. The impact of isolation and quarantine has been profound for older people and people living with

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2 For publications about the impact of the AOP see [http://artscouncil-ni.org/the-arts/participatory-arts1/arts-and-older-people/publications](http://artscouncil-ni.org/the-arts/participatory-arts1/arts-and-older-people/publications)

3 Videos from AOP: [https://www.youtube.com/playlist?list=PLSNEW6tJw5L5wMO0WR1f6VcxuTGkSMQOz](https://www.youtube.com/playlist?list=PLSNEW6tJw5L5wMO0WR1f6VcxuTGkSMQOz)
dementia. Over-represented in incidence and mortality rates people living with
dementia are recognised as requiring extra care and close monitoring to
reported deterioration in mental health for people living with dementia. Di
Santo et al, (2020) noted decline in cognitive function of people diagnosed with
dementia and others who did not have dementia.

Reflective of the older age profile, the multiple morbidities of residents, and
the challenges for people with dementia to adhere to social distancing
residential care sectors were clearly high risk for COVID-19 (Livingston et al.
2020). This fact quickly became apparent in the emergence of large clusters
and outbreaks of COVID-19 infection, across the residential care sector. To try
and protect people living in residential settings from COVID-19 —residents lost
their liberty and freedom to socialise with family, friends and frequently their
fellow residents. Despite being locked away from the rest of the world and
cared for by people dressed in masks and visors all too often the promised
safety did not materialise. Of the total number of COVID-19 related deaths (N=
2,905) in NI 1,006 people who died were care home residents. Most Covid-19
related deaths occurred in hospital (N=1,910), including the deaths of 236 care
home residents.⁴

Figure (1)

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It is generally acknowledged that care home residents and workers have had a particularly brutal and injurious experience of the COVID-19 pandemic (Suárez-González, 2020). In the past 12 months an epidemiological lexicon with words such as incidence, prevalence, incubation, and quarantine have become part of everyday parlance. Within residential care, essential public health measures such as isolation of people who have tested positive for Coronavirus Covid-19 and quarantining of close contacts can prove to be challenging.

The lack of capacity within the residential sector to control and manage infectious diseases was evident pre-Covid (Lee et al., 2020). Chief amongst these deficits was balancing the rights and needs of residents to move freely with the need to ensure effective isolation during disease outbreaks. A recent paper (Iaboni et al., 2020) highlights the challenges in “achieving safe, effective and compassionate quarantine or isolation of older adults with dementia in nursing homes.” The authors use a ‘case vignette’ of a female nursing home resident with dementia to describe the various approaches that were used to ensure effective quarantine.5 Significantly the care plan included “providing math worksheets and colouring pages, and playing movies and music on a tablet.” (Iaboni et al., 2020: 837). Unfortunately, the paper is short and doesn’t provide detail as to how these tools were used (if at all). There is however detail and acceptance of physical restraint and medication to ensure that the resident completed quarantine.

“She was restrained at intervals no longer than 2 hours, and was monitored and socially engaged by staff every 15 minutes for the first hour and every 30 minutes thereafter.” (Iaboni et al., 2020: 837)

Dementia care has achieved great advances in recent years, with person centred care and use of non-pharmacological interventions recognised as being best practice. The full impact of COVID-19 on care for people with dementia is not yet known but preliminary studies (Suárez-González, 2020) point to an increase in the use of antipsychotics and other related medications. In March 2020, a team of specialists from the Dementia Care and Research Centre, Peking University wrote an open letter to the British Medical Journal (Wang, et al, 2020) in which they highlighted the challenges and risks posed by COVID-19 for people living with dementia. Drawing on their experience of the pandemic the authors advocated a multi-disciplinary approach that would consider the mental health and wellbeing of people in residential care. Chief amongst the

5 She had been designated a close contact of another resident who had tested positive for the COVID-19
recommendations was active engagement of family members in care delivery and alleviating isolation.

Proactive and innovative, working against this bleak and challenging backdrop throughout the pandemic artists across Northern Ireland have used myriad ways to make the arts accessible to people living in residential care settings. In some instances, this has meant artistic performances in carparks and some artists have harnessed the power of technology to work remotely with people in residential via Zoom and other media. In addition, pre-COVID work of the Arts and Older People Programme (AOP) has enabled some care homes to be proactive in using the arts to alleviate isolation and loneliness for residents. O’Sullivan et al. (2021) argue that the pandemic has resulted in a greater understanding, across society, with regards to challenges and impact of social isolation on health and wellbeing. The authors argue for a global focus on loneliness and social isolation as public health priorities.

It is anticipated that by giving voice to the people best placed to tell us about their experience this study will go some way to informing future policy decisions. By focusing on people and settings with AOP involvement the study will help illuminate how the arts can be used to promote dignity of people affected by dementia and those living in residential care.

“I don't think we can solve poverty. I don't think we can solve hunger. I don't think we can solve mental ill health. But what we can do is alleviate some of the feelings that come with that and provide a sort of escape or a support.”

(Artist 2, March 2021)

3. Aim and Objectives.

3.1 Aim
To understand what role the arts can play in supporting the mental health and wellbeing of care home residents in the future, with a particular focus on people living with dementia.

3.2 Objectives
The work is underpinned by five key objectives:

A. To explore the impact of COVID-19 on people living in residential care homes across Northern Ireland.
B. To explore the levels of arts engagement possible during the pandemic and where relevant, what impact its absence has had on staff, residents, and family members.
C. To explore what role the arts can play in supporting/enhancing care provision in homes post COVID and what supports are needed to establish this.

D. To draw on existing practice as evidence, explore the artistic and technological response of arts organisations and artists working with older people in care home settings.

E. To draw-up series of practical recommendations to inform good practice in programme design for arts organisations and artists working in care home settings.

4. Methodology

Drawing on case study methodology (Yin, 2013) the study built on established networks across the arts, dementia, and residential care sectors to recruit people for interview. The format and focus of interviews drew on the extant literature of COVID-19 in residential care, expert knowledge of the sector and management of the COVID-19 pandemic in NI.

A total of 12 semi-structured interviews were completed (figure 2). In adherence to COVID-19 restrictions all interviews were carried out remotely. Due to the potential for ethical issues in carrying out remote interviews, no people living in residential care participated in the study. A convenience sampling approach was used to recruit participants. This approach drew on the author’s extensive networks within the AOP programme and the field of ageing and dementia care. The study participants were based in different locations across NI and each had experience of different residential and care settings.

![Bar chart](image)

Two of the interviewees were family carers, another was from the organisation Care Home & Support NI (CHASNI) that supports people with family members
living in residential care. Four care workers working in residential care were interviewed - a nurse and three health care assistants, one of whom worked both in the community and residential care. The care workers ranged in age from a 17-year-old schoolgirl to two women aged in their 60s. Three interviewees were from arts organisations involved with the AOP. An empowerment officer from Dementia NI provided powerful insights into experiences of people living with dementia. Interviews lasted between 45 and 90 minutes. The longest interview was with an 80-year-old woman who spent extensive periods in hospitals, rehabilitation units and residential care settings in 2020. This powerful first-hand account provided insights into the lived experience of isolation and loneliness and the importance of empathy and kindness in promoting dignity.

As a ‘service impact evaluation’ the study did not require research ethics approval\(^6\). Nevertheless, it did adhere to ‘best practice’ standards in working with older and vulnerable groups. The principles of informed consent, confidentiality and anonymity governed all actions. Interviews were carried out by telephone and with the consent of participants digitally recorded. Identity of participants is known only by Lynch. Interviewees were guaranteed anonymity and apart from Dementia NI, CHASNI, and one reference to the Royal Victoria Hospital Belfast\(^7\), no organisations or care settings are identified.

Interviews were transcribed and immersion in this content enabled analysis and categories to “flow from the data” (Hsieh and Shannon, 2005 p.1279).

5. Findings
The interviews yielded rich, powerful, and poignant insights into the lives of people living in residential care during the COVID-19 pandemic. There was strong coherence and consistency in the observations and commentaries shared by all the interviewees.

The study findings are discussed under six headings: (1) isolation and loneliness, (2) environment, (3) feeling connected, (4) fear, (5) dementia, and (6) the arts. In keeping with the goal of giving voice to the people living and working in residential care verbatim quotations are used.

\(^6\) Office for Research Ethics Committees Northern Ireland (ORECNI)

\(^7\) The treatment received from staff at the Royal hospital was highly commended by interviewee and she requested that the acknowledgement be made public.
5.1 Isolation and loneliness

“We weren't aware of any families where it was a gradual lock down. It was just locked down. You'll remember The Commissioner for Older People used terms like ‘a ring of steel around our homes and our older people’. Families did expect this to be a matter of weeks or a matter of months, they didn't think a year that they would be in the same position.”

CHASNI

Given the strict isolation measures within the residential care it is not surprising that isolation and its close relation loneliness was the major theme to emerge.

“There would have been the loneliness in the fact that you didn't, you couldn't have visitors. You couldn't have any family.” (Woman aged-80-years)

There was recognition amongst all interviewees that isolation “caused so much, obviously, loneliness for the residents” (Artist 1).

The restrictions on movement were reported as taking a toll on physical and mental health and wellbeing:

“Because she's not moving about the same. She's sitting on the chair. There were days I went in and she would say 'I was that scunnered the day, I just lay in bed for an hour this afternoon'”. (Care Assistant 3).

A common refrain was the notion that due to the isolation and the loneliness that accompanied some residents give up the will to live:

“I would safely say a lot of our wee patients have died of broken hearts.” (Care Assistant 1).

This observation was echoed in the interview with CHASNI where there were stories of people living in residential care just ‘giving up’ through loneliness.

“People give up. We have cases where, you know, we have people separated from families and they just they stop, they stop eating. They don't talk. They become incontinent... So, they're sleeping all day that when a person with a cognitive ability, especially an older person, when they give up, it's just it's a very rapid decline. It's not something that happens very slowly. It's something that happens very, very quickly.”
Constrained by the regulations, all the care workers conscious of the loneliness that residents experienced were deeply moved by the scenes that they have witnessed over the last year.

“It is so sad seeing residents not being able to have that time with their family member. Especially when they need it most and they are feeling their loneliness and they are feeling abandoned.” (Care Assistant 4).

It was with deep emotion that care assistant (1) described how some residents:

“Just give up, it just gets to the stage where they don't want to get out of bed. They won't eat and all you could do is encourage and encourage them to eat and drink and then they just don’t.”

Cognisant of the delicate balance between preventing transmission of COVID-19 and witnessing the impact of social isolation and loneliness care workers were mindful of how little actual time some residents had left.

“A lot of them have not much hope because they're at the end of their lives and they're not sure they'll ever see it [COVID] come to an end.” (Care Assistant 3).

Yet, simultaneously constrained by public health regulations were faced with arduous ethical dilemmas.

“I think it's so important that residents get to see their family members and not from behind the screen, and not wearing PPE. A lot of them are old and a lot of them are near their death bed, as sad as that is, a lot of them are.” (Care assistant 4)

The loss of human touch was a recurring theme. One the family carers identified touch and hugging as the ‘big things’ missing from the past year.

“The big things that I missed that touch on a shoulder, you know. Hugging in particular. You know, holding someone's hand or shaking someone's hand.” (Family Carer 2).

At times empathy and the innate human response to the distress of those being cared for trumped the rules. The 80-year-old woman described an extremely low moment during a period of quarantine and how much she appreciated the humane reaction of the care assistant:

“I had just a minute ... sort of 'why is this happening?' You know, because you had time to think, and that was one of the days. A very nice girl, one of the
carers came. She sat with me and hugged me, you know, to try to, you know, say that this [time] will go past.”

The transformative impact of human contact was also evident in a poignant description of how one resident, even though she was dying, gained a massive psychological and physical boost by virtue of receiving a visitor.

“There was a wee lady and she had COVID and she kind of came back from it. But, you know, she still wasn't 100 percent. The manager had said ‘look we think she’s end of life and we're going to let the family in’. So, we let her niece in. The niece came in and spent a couple of hours in the room with her. When niece left and I went in to check if she was OK. I walked into the room and I goes, ‘oh, my God’, and she goes to me ‘what's wrong?’ And I swear, she looked gorgeous. She was just glowing. And I said, 'you look gorgeous' and she goes ‘do you think so?’ And I goes 'Do you feel happy because you saw your niece?' cause she would be very, very close to her niece, so she would. And she said: 'it has made me so happy'. I must have sat on the side of bed talking to her for half an hour. I just could not get over how beautiful she looked. And that was just after seeing her family member. Her wee face and she was smiling, and she just looked gorgeous.” (Care Assistant 1)

The isolation of residents and separation from family was difficult.

“There's a sense of personal guilt in not being able to go and see your family. I see photos of him, and we try to do telephone calls, but it's quite late-stage dementia that he has. So, he is not really great on the phone.” (Family Carer 2)

The forced separation was also credited with negative impact on health and wellbeing of wider family members. One family carer recalled how a friend had expressed concern about the impact on that the situation was having.

“It was awful. X said to me ‘I'm really worried about your mental health'. I wasn't feeling that I was coping either. I felt I had separation anxiety from not being able to visit my mum. I had no part in her well-being. I wasn't allowed to hug her, visit her, laugh with her, cry with her. She lost my daddy, you know, a year before lockdown and had just started to talk about him... I went to bed at night thinking about her. I woke in the middle of the night crying about her.” (Family Carer 1).

The experience described above was a phenomenon familiar to the nurse. Working in residential care she was acutely aware of the toll that separation was taking on family carers:
“People have entrusted people into our care, especially women who were in the 60s, who have looked after their mothers. They have been their sole carer and then suddenly they were cut off completely where they couldn't see them at all.”

The nurse also spoke poignantly about the enforced exclusion of spouses married for over half a century:

“We had a lot of people who passed away, some of them have been married for 50 years. We had one man upstairs he'd been married for 60 years and for his wife, you know not to be there – that was very hard.”

Having experienced quarantine various times in 2020 the 80-year-old woman was very conscious of the fact that she was alone:

“You were there on your own and you knew that the staff didn’t have time to come and be there every minute of the day; so, you were quite lonely on your own.”

The 80-year-old woman described living in a room on her own completely removed from other residents. When quarantine was completed, due to social distancing measures, her interaction with other residents remained limited and meals were eaten alone in her room. This experience was borne out in other interviews. The limited nature of the social engagement in residential care, even at times of low prevalence, is described by Care Assistant (3)

“They were still moving freely amongst each other within the building. In saying that when they did meet in the public areas, they did socially distance. The chairs were all separated six feet apart.”

Communication for people with sensory and/or cognitive impairment is challenging at the best of times. Imposition of distance can render communication impossible. The loneliness in such an environment and the additional challenges of maintaining social distance or quarantine\(^8\) for people with dementia were a recurring motif:

“... keeping them in their own rooms, having no crossover of staff. You know, they have three different sections ... the dementia unit and then they have like two general units with two different living rooms.” (Artist 1).

\(^8\) Mandatory quarantine for 14 days is required for all admissions and for any close contacts of COVID-19 cases
“Keeping them two metres apart in the sitting room, you know, is very hard.”
(Care Assistant 1).

It was evident that there was little if any supports available to help residents and staff cope with the strict isolation regime:

“She came in for respite. Respite is meant to be a two-week period. During that two-week period, she had to isolate. She had dementia and was very, very confused. We found her out of her room a lot. She had wandered out of her room. We had to bring her back into the room. I think she felt very restricted and confused. She didn't know where she was. She felt lonely. She couldn't see her family. Her family couldn't come see her. She would constantly ask to see her family. She'd keep saying – 'I just feel very lonely’. She would get very emotional all the time. It was very hard for us to calm her down and know what to do. We couldn't do much, because she was confined to her room.” (Care Assistant 4).

Reflective of their previous engagement with residential homes all the artists felt that they could have used their skills to help. Artist three described this exasperation eloquently:

“You know, and that has been one of the things that I've grappled with is not being able to provide, you know, the engagement and the work that I do when I was most needed. And that's something that I struggle with mentally.”

It was evident that carers did not have the specialist knowledge and skills that would have equipped them to care more effectively for people with dementia through the pandemic. Although staff had access to training it was not dementia specific.

“It’s not really about dementia. It’s all different things like safeguarding and moving and handling, infection control and lots of different things. You wouldn’t just do, like all dementia really you wouldn’t do a full day on dementia.” Care Assistant (1)

Care assistant (1) has been working for eight years in the same place and had developed close bonds with residents, many of whom died during a COVID outbreak in 2020. It was evident in her interview that the challenge of caring for people infected with COVID-19 was exacerbated by the isolation that she witnessed, candid and clearly emotional she explained:
“It’s hard watching someone that you cared for, for so long, maybe three, four years, and you just watched them go and die. You know, you’re just watching them going down. Every morning you go in, you know, you’re just going in [thinking] ‘how’s this wee critter today?’ It’s literally heart-breaking. And, you know, people say ‘when you leave, you leave it at the door’. But you don’t. You take it home with you and when you are in bed at night. It’s just you’re just constantly thinking, you know, are they going to be there in the morning? And then sometimes you think ‘maybe it’ll be better if you weren’t there’. It’s just heart-breaking. You know, it’s heart-breaking. And what’s even more heart-breaking is they have none of their family with them. That for me is heart-breaking because I go in and I can do my job and I walk out, and I go to the next resident but when I leave that wee resident, they’re in that room on their own. When I leave them, they are on their own. That’s the hardest part. I think, every family should have their loved ones with them. It’s hard because I know that you cannot let them in because of COVID but I think if that was my mummy, or my daddy and they were in a home, I would break my heart if I couldn’t get in just even just to sit and hold their wee hand. OK, we can facetime them. And you know things like that but it’s not the same.” Care Assistant (1)

Reflective of the deep relationships she has built over years working with residential homes Artist One spoke with great emotion about living through the pandemic. Deeply aware of what her colleagues in residential care were coping with she said:

“I felt really guilty. If people weren’t following guidelines or you know, just not taking it seriously. I’ve got to say, I really struggled with that. And I kept on saying to people: ‘go into care homes there, speak to nurses and staff and then you would understand just how difficult and horrific it is. What we’re being asked to do is so relatively easy.’ And I’m not saying easy flippantly, because it’s not easy, but it definitely made me feel, I think, definitely more awareness.”

There was widespread consensus that the pressures in residential homes were not well reflected, or covered in detail, in mainstream media coverage of the pandemic. Consequently, even though they were working on the frontline caring for seriously ill, and dying residents, the care workers often felt isolated, invisible, and ignored. Working against the backdrop of widespread media coverage and public displays of support for the NHS, Care assistant (1) said:

“...listening to the news. It's always hospitals. The staff in the hospitals. They're always getting [attention], you never hear what the care assistants go through. You never hear care assistants mentioned.”
The lack of understanding amongst the public of the reality of COVID-19 in residential care was universally acknowledged. The nurse was sanguine and generous in her account:

“I don't get angry at other people because I know that people have their own wee world and it's good that they can do that. Because you wouldn't want people to be exposed to see that, because it can break your spirit. You wouldn't want people to see that, you know, that's almost like a horror of people taking their last breath, you're interceding for them for their family. And you're just hoping that you'll be able to spend some time with them. And that they don’t pass away by themselves, especially if they are very afraid and that they pass away without struggling for breath. And you are trying to make them as comfortable as possible and trying to address other people who have the same illness in the home.”

There was an awareness and resignation amongst interviewees that the pandemic was far from over and the steps needed to be taken to address the negative impact that stringent public health measures were having:

“We still have such a long way to go, which is truly heart-breaking. And the more this continues the isolation and the loneliness, and the deaths caused by it will eventually and absolutely outweigh the number of deaths from COVID.”
(Family Carer 1).

It was clear that working in the unrelenting harsh environment was taking a toll on staff too:

“You would have talked to the other girls and you would have been crying and you would have taken it home with you. You always took it home with you. You would have gone to bed at night, you know, it's just flashbacks, it just keeps playing in your head. And you keep saying to yourself, is there anything I could have done differently? (Care Assistant 1)

Significantly, and likely a reflection of their long history of working with residential homes the artists were in fact acutely aware of the emotional and physical burden of work and the impact of isolation on care home staff:

“Tо bе sо cut off tо bе felt and thе stаff fеlt rеаllу likе thеу wеrе bеing lеft bеhіnd.” (Artist 1).

Conscious of the value of their work and their potential to help residents and staff the artists were honing their skills developing online tools and resources:
"I've been talking a lot and thinking about doing if we're able to provide things for isolated older people by themselves, can we also provide long term arts workshops that are on Zoom or whatever for the care homes? I'm very aware that care homes probably won't be able to have people come in for a very long time. So, we're going to have to bite the bullet and do something online with them, if that is, of course, done." (Artist 2)

In September 2020, the Minister of health Robin Swann introduced the Care Partner scheme to enable a designated relative or carer to visit a resident. In February 2021 Family Carer (1) was permitted to visit her mother inside the residential home for the first time in 11 months:

"The 16th of March 2020 was the last day I visited my mum in a care home. Looking at my mum today, you know, she was joking and laughing. Not making much of an attempt to get out of her seat but she has been in it for 11 months." (Family Carer 1)

5.2 Environment
"I just lay in my bed and look at their backs walking up the corridor. All I could see was the nursing staff walking up and down. But as soon as they passed my chair they disappeared. Because I couldn't see them. I just thought about, you know, lunchtime, then teatime, then night-time. And then another day. Another day."

(80-year-old woman)

Time and again the environment was cited as a crucial factor in promoting dignity and preventing social inclusion. Environment included the physical layout of buildings, rooms, and gardens. It also included access to technology, the use of Personal Protective Equipment (PPE) and the impact of by Perspex screens and windows on visits and communication with people who have dementia and/or sensory impairment. The importance of empathy and kindness are also highlighted for their contribution to the emotional environment and emerged as vital in promoting human dignity.

"If you don’t have the kindness ... you just feel you're just a number it's soul destroying, just soul destroying." (Woman aged 80 years).

5.2.1 Dignity
The quotation at the beginning of this section describes an experience in a NI teaching hospital. It highlights the importance of environment in promoting dignity and the experience illustrates how short comings may result from lack of thought or empathy on the part of staff. Recovering from hip surgery during
the height of pandemic in autumn 2020 the 80-year-old patient was being nursed in a room that had neither television nor radio. Mobile telephone reception was virtually non-existent and due to the positioning of furniture the patient only had a rear view of staff. When her son visited, to bring change of clothes due to COVID-19 restrictions he was not permitted to cross the threshold of the room.

“I felt you know, the loneliness, with no television, no telephone reception and the fact that my son could come only to the door, and I couldn’t see him, I could talk to him with my back to him.” (Woman aged-80-years)

Instantly recognising the problem, a hospital manager placed an armchair in a position with a vantage point. This simple change provided an unobstructed view out of the room and immediately enhanced the patient’s sense of connection and wellbeing:

“And the girl brought an armchair and put it in such a way that I could look down the corridor. And the first time that M came back with my clothes I could see his face and he could talk to me. And that was a big, big plus.”

(80-year-old woman).

Reflecting on the experience the woman expressed dismay that staff had not recognised her predicament from the outset. Characterising the days that she had spent in sensory and physical isolation as the most difficult during her eventful year. When asked how she felt about the staff she elaborated:

“Well that they’re lacking in humanity. I just thought that they were very selfish. Yes. And that it’s just a job to them. Yes, that’s right. And they don’t care whether the patient was feeling lonely or anything.” (80-year-old woman).

It is worthy of note that this was the only negative experience that the woman reported during her various extended stays in hospitals (x3), a rehabilitation centre and residential homes (x2) in 2020. Stories of ‘kindnesses’ were the major theme throughout her interview. Relating an incident in another teaching hospital she requested that the institution be named so touched was she by the kindness that she had experienced there:

“The nursing staff were more than kind in the Royal Hospital. When the nurse came in the morning, she said to me, ‘do you not have slippers?’ And I said, ‘no, I didn’t have time to get them’. She brought a box, a perfectly new box with a pair of slippers for me. And she was so kind. I told her that I would try and tell people about it when I came out. And she said, ‘that would be lovely because we’d get so much, you know, of different people complaining’.”
Genuine kindness, empathy, and respect for the people for whom they were caring was evident in interviews with all the carers.

“I think that during COVID the biggest thing that you need to do is, be kind, be loving, be compassionate, be patient. And those are probably the things that I think about every day when I go in. You have to be patient. You have to be kind at all times because this is a person’s life, and you are caring for them. You’re not above them. Although they have dementia they are not stupid. They know you need to treat them as a person, not as a child. They have years above me.” (Care Assistant 4).

Aged in her fifties Care Assistant three has 40 years of experience. She identified empathy and trust as being crucial to her work and was fulsome in her praise of the insights and abilities of her younger colleagues:

“Those wee girls I work with although they’re younger than me, they’re very, very, good. And they are tuned in, they are sharp; sharp as knives. They really are. I mean, they might pick up something before I would pick it up.”

The importance of human relationships was put in sharp relief against the stark reality of isolation for people living in residential care. Reflective of the enforced nature of isolation within residential settings terminology of prison was not uncommon.

“She has said to me over the summer, ‘it’s like prison here now. I used to like it’. (Family Carer 1).

Staff used similar language to describe the stringent rules that were in place to facilitate visits by family.

“Even when restrictions eased a little during summer 2020: When things kind of settled down and they [family] were allowed to come into the dining room with, you know, the thing [Perspex] between them. They weren't allowed to touch them or anything. But, you know, it's hard. And only one family member is allowed to come in. (Care Assistant 1).

“It would great if there was an outside garden area where people could go out to. But for our people upstairs - it is like a cage. God forgive me for saying it. But it is.” (Nurse).

COVID-19 regulations and the potential risk of infection to residents meant that stringent quarantine rules were applied to anyone who left the home for whatever reason. So, for example, when in the autumn of 2020 carer one’s mother left the home for a couple of hours to visit her daughter, on return to
the home she would be subjected to strict quarantine for 14 days. In addition, the clothes that she had been wearing were treated as potential source of infection and therefore removed. This process was perceived by the 91-year-old-woman as degrading and traumatic:

“They took every stitch off me H because I was at your house’. I said, oh, mummy, don’t worry about it. It's just to make sure that you haven’t gotten got infected while you have been at my house.” (Family Carer 1)

During the pandemic and isolation little things assume major importance. For example, during her first stay in a residential home the 80-year-old woman described the trepidation with which she handed over her clothes to be washed. Assuming that they would be returned in a sorry state it was to her immense delight the clothes were returned in pristine condition. A discovery that gave her an enormous psychological boost:

“Oh that felt terrific. The first time I got the clothes back when I saw them. I couldn’t believe it. It was just as if I had washed and ironed them myself.” (Woman aged-80-years).

Family carers were clearly appreciative of the empathy and care that they witnessed from care workers. They were also mindful of the personal toll that caring in such a harsh environment was taking on them:

“Some staff members they left the job because they just couldn't cope with the situation. With watching the isolation because they form connexions. And those connexions and attachments can run very deep.” (Family Carer 1)

In her interview the 80-year-old woman highlighted the number of times that she had received care from migrant health workers and how appreciative she was of their kindness. She mentioned inter-alia doctors, nurses, and carers from Black and Minority Ethnic (BAME) backgrounds. The interview extract on the next page captures a flavour of the kindness and care that she experienced. That kindness engendered feelings of great trust in the carers and made her feel safe.
5.2.2 Death and dying

The demographic profile of people living in residential care means that death is not a rare occurrence. COVID-19 however saw mortality rates increase dramatically. All of the care workers talked about death and the ways in which they had tried to be with people and comfort them:

“You would you know when it’s coming to the last and you would have stayed with them and held their wee hand and just rubbed their wee face and talked to them.” (Care Assistant 1)

Due to COVID-19 regulations, carers have assumed roles that would previously have been the preserve of family members. Including being the only person there when residents die. Carer (4) still a teenager herself is acutely aware of the pathos of this situation:

“The other day, one of the residents I was working with, she died, and she died in my arms. I was very upset. ... It is so hard for family members to come and see their mum and dad. And when they do get to come see them it’s not very personal. And I think that those regulations for care homes should be reviewed.” (Care Assistant 4)

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**Woman aged-80-years:** At no time did I feel that I didn’t want to be there, or I didn’t want to be under their care, because they were so kind.

**Interviewer:** And what made them kind? Paint a picture of what that means?

**Woman aged-80-years:** Well, it meant that I got it into my head that these young boys were people, who would have been very caring to their own elderly family. Because of them being from the Philippines, I don’t know why, but they were they were a lovely, caring people.

**Interviewer:** Was it the way that they spoke to you?

**Woman aged-80-years:** it was the care they gave me? Yes, the care they gave me. And they didn’t make you feel that you were any trouble to them, or that they didn’t want to do it. They were so caring, and I didn’t feel in the slightest risk —that they were young boys, and they were looking after me—that didn’t enter my head at all.

**Interviewer:** OK, and did you feel safe?

**Woman aged-80-years:** Oh, I felt very safe with them. They were just unbelievably caring.
The absence of rituals associated with a dignified death was difficult for staff:

“It's hard for us, you know, it's hard. When they die of COVID, you know, families aren't allowed in because it's COVID. So, when they die, you're not allowed to change their night dress or anything and the undertakers literally come and put them into the coffin. It is heart-breaking.” (Care Assistant 1)

The lack of ritual around death proved difficult for others with dementia in their understanding of what has happened:

“Some of our members have gone into residential care and some of our members have died during the pandemic. Not necessarily COVID related. But it's been difficult on the members. They felt that they didn't necessarily get the proper chance to say goodbye, or have a proper send-off, or even attend the funeral and that had a severe impact on them.” (DementiaNI)

5.2.3 COVID-19 Safety Measures

COVID-19 safety measures quickly saw communication mediated through Perspex screens and windows. Although powerful tools in the reduction of aerosol transmission of the Coronavirus these measures are not dementia friendly. The barriers restrict sound, and the reflective nature of glass/Perspex can result in distorted and disturbing visual effects design for people with dementia. Drawing on feedback from members and carers DementiaNI was critical of the negative impact of the Perspex screens:

“It's actually probably even more distressing for both the person with dementia, their carer on the other side of the screen.”

Family carers echoed this observation and spoke about the guilt and angst they experienced in visiting relatives. Family carer two articulated the dilemma he experienced in standing outside a window to visit a relative who has dementia:

“There's the barrier of the glass itself, but it's a bigger barrier and there's reflections of yourself and the windows you're looking in. I mean, it's pretty cold standing outside. You're worried about him being inside with this draught coming through. He can't really see you too well. And, you know, a few times he was distressed thinking what the hell's he doing in the window? He doesn't quite get it. And in many ways, you know, I felt more guilty at doing that. And I was wondering, was it solving my conscience.”

Visits outside windows became part of the everyday life for family carers who went to great lengths to maintain contact and semblance of normality:
“I couldn’t do any more than I was doing. I was baking during the week and taking her wee treats at the weekend. Bits that she requested like wheaten bread, sausage rolls. One night it was pizza. My son ordered a six-inch pizza and I sat outside her window while she had a pizza.” (Family Carer 1)

The impact of the barriers such as windows and Perspex screens on communication for people with sensory impairment was a recurring theme:

“…other people with hearing difficulties it’s just not working for them either because there is that screen and that the sound can’t come through as well. And then there is the reflection, which means that lip reading becomes more difficult.” (DementiaNI).

Carers were also acutely aware of how difficult it was for residents to have effective communication with family through windows and screens. They spoke openly about the dilemmas that they faced:

“There was a wee man had his 80th birthday a couple of weeks ago and it [the party] was all at the window and you’re not allowed to open the windows. It’s hard to watch them. And, you know, we can’t open the windows because if anything happens [COVID infection], then you’d never forgive yourself, you know.” (Care Assistant 1). In the summer when restrictions relaxed a little, families could sometimes meet outside, but an Irish summer does not guarantee heat. Describing her mother’s 91st birthday celebration carer recalled: “…but it was a cool day, Mum was freezing. I remember thinking the wind was blowing through the pergola and we were all cool. But I was especially concerned about her, of course. I think we’ve got about three quarters of an hour. We didn’t get long, but we got long enough because the temperature wasn’t very good.”

The care workers also talked about the challenges of communicating effectively with residents whilst wearing Personal Protective Equipment (PPE). Care assistant (1) articulated the challenges for residents and staff:

“It’s like when you have a mask on, and you have the shield on and you’re trying to talk to the wee patients that you’ve known for years and they can’t hear you right. And you know yourself some of them is hard of hearing as it is. And then you try to talk to them, and they can’t hear you. And then you are kind of shouting and then they go to you ‘what are you shouting for?’ You know, you don’t mean to it’s just because you have all this stuff on you, you know, which is hard too.”
Artists were hearing from their care worker colleagues about the challenges of maintaining health and wellbeing within the context of COVID-19 regulations.

“I know from the staff just how much of a toll it has taken on all of the residents. And for the dementia unit. They really did not understand what was going on. It really affected their dementia and their mental health. Because all of a sudden, all of their routines were changed overnight. Staff wearing masks.

And in a care setting when you’re working with older people, your facial expression is so important. There are hearing difficulties as well. People rely on seeing you. When someone is smiling at you and comforting you and reassuring you, it all comes from your facial expressions. So, I do know that X said the dementia unit certainly found it hard. The residents had been really unsettled at the very start. They had to prioritise their physical well-being. So, they really struggled to be able to do all of it, because if you’re looking after someone, it’s not just the physical activities. You know, it’s ensuring that their mental health and everything else.” (Artist 1)

5.2.4 Design
The variations in design and structures between and within residential homes was identified as a major factor in promoting social inclusion or exacerbating isolation and feelings of loneliness. During the summer when COVID-19 restrictions eased a little, those homes with conservatories or French doors leading out to gardens or patios seemed to provide ideal location for open air concerts and other performances.

“It depended really, you know, on the set up of the care home. Some of them, have dining rooms with like French doors that opened to the outside. And you could perform in front of them. A lot of them didn’t have that. So, it [performances] was just sort of at the front entrance. And they opened all the windows so that it could be heard from the rooms.” (Artist 2)

Outdoor performances, while ideal during COVID-19, in NI such performances were weather dependent and sometimes logistics proved too difficult for artists to co-ordinate:

“I would say that has its own challenges and restrictions. With you know the weather... there can be tuning difficulties and getting rained on if you don’t have a gazebo. We went through all those different scenarios and we had spoken to people in the day centre and some of the guys up there [residential care]. But we would feel safer if we just held off.” (Artist 3).
Conscious of the pressures faced by their colleagues working in residential care, artists reported feelings of impotency and did their best to keep communication open:

“They were trying to keep their residents isolated within their own rooms. So, they weren’t using common areas anymore. So, it was really difficult to try and get engagement with them. I just kept in contact.” (Artist 1).

Recognising that COVID-19 restrictions were going to be around for some time, some arts organisations took a strategic approach. Assessing environment of homes to deliver outdoor performances against the backdrop of unpredictable weather:

“Waiting for a good day, which was an interesting one in itself... waiting for a good day. And then we would bring the act with a P.A. system to whatever part of that care home externally could be viewed by the most residents. One of the things that I did was to scope out with each care home. Do you have an outdoor space? Is it paved or does it have grass? Do you have a sort of conservatory or do you not have anywhere that they can open the doors and access? Obviously, it was the summer, so it was warmer.” (Artist 2)

5.2.5 Location

Location, location, location. The location of a resident’s room proved to be vital in facilitating communication and access to family during the height of the pandemic. A daughter shared her experiences of visiting her mother every single day:

“Rain and the snow. She is on the ground floor and to maintain that visual contact. I did that every day, every single day. And I didn't do it begrudgingly and I'm not doing it to sound good, I did it because I loved her, and I missed her”. (Family Carer 1).

Those residents who lived in ground floor rooms were in prime position. So great was the impact of floor level that the nurse declared that:

“All homes like should all be on one level.”

By way of an explanation she elaborated:

“Some people who were down in the bottom floor were lucky because the families come to the windows, you know, to the outside and say hello. The ones
“upstairs in the dementia unit you didn’t have any of that. So, they had no contact at all.”

The 80-year-old woman recounted a telephone conversation that she had had recently with a friend, who is currently living in a residential home. The friend was so lonely that she cried during the phone call. Her loneliness appeared to be exacerbated by location in a first-floor room making face to face contact with her family all nigh impossible.

“Well, they can’t visit her because of the COVID and she’s upstairs. When they come it means she has to get up and walk over to the window and talk to them. And they don’t approve of that. Oh no they don’t approve of that; they don’t like people coming and talking to them in the window. I suppose it’s in case it disturbs other patients [residents].”

The nurse explained how she used classical musical to help fill the void of isolation and loneliness for residents, particularly in areas where people are nonverbal, ill, or dying. She said other staff members had commented on how it improved the atmosphere:

“when the music came on, he said ‘oh it’s a nice atmosphere’, because some of the music was so mellow and without words and sometimes you just find it actually helps the person themselves, even though they’re not talking to you, the person who is very ill, sometimes it does create a peaceful atmosphere. Away from that clinical and for the family as well, you know it gives a therapeutic ambience. You hope so anyway.”

5.2.6 Digital divide

COVID-19 has accelerated the use of technology and virtual communication. The potential for use in residential settings appears to have been limited due to various factors including lack of equipment, staff shortages and capacity to use the technology.

“A national problem for care homes was really the fact that they were left extremely short staffed. They just didn’t have the staff to even facilitate anything online. They don’t have the equipment, there’s a lack of laptops, and iPads.” (Artist 1)

All the care workers have been working under enormous pressure to ensure that all residents were cared for. The critical situation is captured in care assistant one’s candid description (see box on the next page). The characterisation of a typical day is borne out in the experience of a family carer.
Her 92-year-old mother was living in residential care and despite daily visits from her daughter, albeit conducted through a closed window: “she was quite vacant. She was almost as if ... she had no communication with anybody, and no physical interaction other than people coming in to help get you dressed in the morning and then bring your meals and then they go, and then they come back and get the tray, and they go again.” Similarly, artists identified the pressures that care workers were under as a major impediment to initiating or advancing any work:

“I got to the stage that the amount of work that we could do with care homes was really limited. There's no doubt about it... they were just exhausted. Absolutely shattered. That was the truth. Yes. They were just beyond exhausted and they were dealing with the day to day themselves and didn't have capacity to really get involved.” (Artist 1)

It was evident that even if there was time for introducing and using technology the infrastructure was not in place.

“There’s digital poverty ... We're all NOT on a level playing field” (Artist 3)

This observation was borne out by staff, family carers and the 80-year-old interviewee.

“Well, some people downstairs, yeah, they have phones, but not many people have like the technology of an iPad or anything.” (Nurse).

“The mobile that mummy had that she was very good at it and broke down and I tried my best to get a replica, which proved to be very difficult. She can't operate this new one but she knows how to answer it, but she can't. You have to be the one to hang up from her because if you allow her to hang up, she hits the red button and turns the whole phone off.” (Family Carer 1).

“I don't text. No, no, no. Just phone calls.” (80-year-old woman)
Conscious of the digital divide and the importance of technology in ensuring safe social contact through the pandemic DementiaNI has developed a dynamic range of online programmes for members. This multi-faceted programme includes provision of equipment, training, and support (see box below).

“At the very start [of the pandemic] members were most concerned about not being able to see their peers anymore and losing contact with other DementiaNI members. We very quickly got on the ball and went online. We started Zoom sessions and put on support groups online.

It's a well-known assumption that people with dementia can't learn something new and DementiaNI have proved that that's very much not the case. Our members who may not have had access to technology before or used a tablet, were able to utilise our tablet loan scheme.” Through this scheme “members were able to receive a tablet from DementiaNI and receive training from our empowerment staff.” They also “receive a dementia friendly guide on how to operate the tablet.” In addition: “if we had a dementia empowered zoom support group that had commenced, and we noticed that one of the members who did have a tablet wasn't attending. We could just click on to it and it would immediately dial into their tablet and start ringing so that they were then able to come on and join us in. And that has gone really well.” (DementiaNI)

5.3 Feeling connected.

“She's got a television. She's got her two seats from home. She has hospital bed she has a photo of daddy and her on the wall. A photo of my son and his wife carrying their toddler. But personal things that would have sat in her living room at home are all away.”

The description above is of a 91 year-old-woman’s room in the residential home where she lives. Paired back to the absolute minimum due to COVID-19 her connection with the outside world a television, a photo of her with her deceased husband and a photo of her grandson and his family. For the best part of a year, apart from phone calls, this woman’s only direct contact with her family was mediated through her bedroom window. Her 63-year-old daughter worked extremely hard to maintain daily contact with her mother throughout the pandemic. Nevertheless, she saw her mother decline. In autumn 2020 following extensive lobbying and on the back of Minister Swann’s Care Partner’s legislation she secured visiting rights to her mother in the home. In her application she reported that:
“My mother’s mental health has gone down. She is becoming distant, she’s vacant, she can’t sleep and she’s not eating. She’s cross. She’s disinterested in living in life. And I said, really, mum is just waiting to die, she gets up every day to sit in that chair to die. And if she doesn’t die that day she goes to bed and she wakes up the next day. So, I said, I really feel for her mental health stimulation and well-being. I need to get in to the home every day.”

Visiting rights granted her mother’s mood improved immensely. In December COVID-19 restrictions had eased and her 91-year-old mother was granted permission to leave the home for Christmas day. Day release from the residential home would mean a 14-day quarantine after. Nevertheless, the joy and happiness she witnesses in her mother was evident from the moment she walked into the house:

“The first thing she said to my husband when she came through the front door was right R I’d like a Bailey’s please.” (Family Carer 1)

There was a pervading sense that people living in residential care felt forgotten about. The absence of visitors and human contact was causing cognitive decline and feelings of intense loneliness. It was evident that residents with dementia were feeling the loss to a greater extent, their situation compounded by the challenges in communication.

“Downstairs in the dementia unit it’s a lot slower. It requires a lot more patience and there are a lot more social skills required when communicating with them. Whereas upstairs it’s a lot easier to make connections. With the residents, downstairs it’s hard, because of their dementia.” (Care Assistant 4)

Although unable to visit inside the homes the artists worked behind the scenes to help residents feel connected to the outside world. In one instance children from a past intergenerational project were encouraged to write to the residents that they knew. These simple personal letters were very well received and were a source of great satisfaction to the artist:

“One of the young boys, he specifically wrote to B [a resident] to say, ‘I hope you’re keeping well. I will miss you’. So that was really lovely. Just to feel like you’re passing on love to them.” (Artist 1).

Another artist had worked with older people living in the community during the phase one of the pandemic to develop a bespoke DVD with music and film clips from circa 1950s. The DVD posted out to people across East Belfast proved to be a huge hit and talking point in the community. Groups of older people
watched it simultaneously in the safety of their own homes. Chatting and reminiscing about it via WhatsApp and telephone. So popular was the DVD that other people requested copies including a woman whose mother was living in residential care:

“I got actually a bit of feedback a couple of days ago, from a girl who had got one [DVD] for her mum who is in a care home. She had got a DVD specifically for her so that she could have it in her room. And she said that her mum is almost non-verbal now. But that the entire time the DVD was on she was dancing and singing... That to me shows the power of the arts. And I think specifically music in this case to be able to impact someone and to help them overcome some sort of physical or mental ailment they have.” (Artist 2)

Working in both residential care and the community Care Assistant three saw her role as bringing social connection to people who were isolated from the world:

“I mean, with all of them, every one of them it is a social thing. You have to try they want to know what’s happening in the world. There’s one wee lady ‘when is this ever going to end?’ you have to try and lift their spirit. ‘Oh, it will end don’t be worrying. Just saw the numbers are going down a wee bit’. It was awful when they were going up because it was oh my God, is there any hope for any of us?”

The same carer identified humour as a powerful tool in developing connections with the people that she is caring for. She used the example of a couple both octogenarians living in the community to illustrate her point. The husband needs extensive support with personal care and his wife is his primary carer, what could be a very arduous situation is lightened through humour:

“Most of the clients do have a sense of humour. You know, there’s one couple and they’re lovely. He is so funny. It’s a pleasure to go to these people, you know, and they always make me giggle. He’ll say, right M (wife) it’s your turn now and her washed and dressed and all already. Just the simple things like that it lifts them, and it lifts us as well.”

Unable to visit her colleagues in residential care but mindful of the pressures that they were working under Artist One made a conscious effort to check in with them regularly:

“You know, because, again, it made her feel connected. Helped her feel that other people understand how difficult it was. We know, that you really do an
amazing job, you are a real joy. And I kept on saying that to them. To let them know that there are people out here thinking about them. It was important to do that because their morale was so low, really low.”

The empowerment officer with DementiaNI credited technology with bolstering sense of community and ‘togetherness’ within the organisation. The use of online media enabled it to develop networks and groups with people from across NI something that would previously have seemed logistically impossible:

“Togetherness. The togetherness that has been shaped by the interactions between the DementiaNI members over the past year and the bonds that they have formed. That has been facilitated because of the technology. It opens doors so much more. Where before members and our groups would have been more geographical based. Zoom has opened doors that we can basically invite anybody from Northern Ireland with a dementia diagnosis to participate as long as they’re able to access the technology to do so. It has opened doors for us and even after things open up again with face-to-face meetings. There will be an element that will remain partly electronic.”

5.4 Fear
People living with dementia are often dealing with feelings of confusion and disorientation. This state of incertitude can result in fear, which is a highly contagious emotion. Significantly all the study participants described being frightened or witnessing fear in others due to COVID-19. People with dementia were concerned that their cognitive function would deteriorate due to the lack of social contact and engagement with other people:

“Everybody was especially scared. They were very concerned about how their dementia might progress quite rapidly due to their lack of ability to go out and socialise as much. They weren’t able to be integrated within their community anymore. And it raised a lot of concerns as to how this might impact and accelerate their dementia.” (DementiaNI)

For care workers who were often caring for residents with COVID-19 there was an omnipresent fear of catching the virus. In the early days of the pandemic fear was exacerbated by uncertainty, lack of knowledge and lack of equipment:

“Initially we didn't have any visors or a protection, but eventually that came out as well. I think probably around about the end of April and May. And it was actually after the first real bad wave that they then started providing us with masks.” (Care Assistant 3).
All workers were frightened of bringing the virus into their own homes and unwittingly passing it on to family members:

“They were living under constant anxiety; they were worried about bringing comfort and they were worried about bringing it out as well. They have families, they have older people themselves. They have relatives. And it was living in constant fear.” (Artist 1)

Carer one painted a vivid picture of the routine that she went through for nine months:

“You knew you were coming home to your family and you’re thinking, you know, I’m carrying this. You are carrying it home with you. There is no two ways about it. So, whenever I was coming home, I would have all my clothes in a bag, you know, it was like a wee cloth bag. I would have put my full uniform into that wee cloth bag and when I come home. I would have set the cloth bag at the at the front door and went straight upstairs for a shower and then come down lifted the cloth bag — I wouldn’t even have opened it — and put the bag and everything into the machine and turned it on. And then you would have been constant cleaning your own house. Doing door handles because I would be coming home from work, I would have been touching the door handles, I would have been touching the light switches. So, you know, OK, so I washed my hands when I was leaving work. But, you know, whenever you're opening that door going home.” (Care Assistant 1)

Care Assistant one eventually tested positive following a large outbreak of COVID-19 in the residential home where she works and despite her rigorous safety measures passed it on to her daughter:

“You waited for your phone to buzz and were nearly afraid to look at your phone in case that it would come back that you were positive. You know, you were just literally petrified. But thankfully we got off for so long. But I suppose it was only a matter of time."

Ironically having spent extended periods of time in different care settings and being tested repeatedly for COVID-19 it was in her own home that the woman-aged-80-years experienced her scariest time. One of the carers who visited her each day at home had tested positive for COVID-19 and for over 10 days she worried that she may have been infected:

“D had given me a bottle of perfume that she doesn’t like and I have it here on my table. And I was pressing it every day for the ten days. I’m sure I must have sprayed it half a dozen times that evening and night to see if I could smell it.
And I kept pressing every day for the ten days. If I don't lose my smell, yes, I'm all right. And that was one of the scariest moments of the last year.” (Woman-aged-80-years)

5.5 Dementia
Dementia was an omnipresent backdrop to the interviews. It was evident that people with dementia experienced profound loneliness and that the enforced isolation was taking its toll.

“Confusing ... because residents don't necessarily know where they are because of the dementia. Especially when they don't have the reassurance from their own family members. It is particularly hard in the sense that maybe they don't understand or know why they're not able to see them [family]. They would usually be alone. We can see them every day. We can talk to them every day, but we're not family members. It's not the same reassurance from us being strangers, wearing masks and visors and aprons and gloves. They're not going to trust you just as quickly as with their families. We find that a lot of the residents would have like wee anger outburst. And they're very hard to calm down.” (Care Assistant 4)

The impact of isolation was reported as taking a toll on cognitive function. This decline was a concern that members of DementiaNI were particularly worried about:

“We have been working with the DementiaNI members on a series called ‘Life in Lockdown’. Where they spoke of their fears and their losses because of what they came through in the pandemic and lockdown.” (DementiaNI.)

In residential homes the impact of isolation on cognitive function was felt acutely. Care Assistant three described deterioration that she observed in a resident.

“She seems to be going back a lot into the past, her sister died with Covid, in March last year. And there was only four people that could go to the funeral. And she wasn't able to go. She talks a lot about her sister and when they were young about boys and stuff. She has just kind of regressed back into her earlier life, you know what I mean?

Meanwhile care Assistant one reflected on the death of a resident and its impact on another.

“There was two ladies who sat together, and they were very friendly. Both of them got it [COVID-19] and one of them passed away. To this day, the other
one would still keep asking, where is she? And we would say, oh, she's in heaven. But she would keep asking about her and talking about her.”

The situation described by care assistants one and three were very real the interpretation of behaviours may also be reflective of lack of understanding and insight into how dementia can manifest. It was evident that care workers were ill equipped to cope with the complexities of COVID-19 containment and prevention. In addition, none of the care workers had received specialist training in dementia and lacunae in their formation was often evident in descriptions. A deeper understanding of dementia may have made caring for residents easier.

Family Carer two was also a musician and experienced in working with older people and people with dementia. Despite this professional background and knowledge, the challenge of maintaining good communication with a person who has dementia within the context of COVID-19 regulations was difficult:

I'm probably ahead of the curve, maybe just with my own work experience, but it's still difficult to make it through to someone with dementia because the barriers are there. And you just know when they're not there. And it's tough, it's tough.”

Responding to the concerns expressed by members DementiaNI has developed a dynamic and successful online programme of arts-based activities:

“At the very beginning of the pandemic, the members had spoken about their anxiety and how some of them felt that it was causing them sleep disturbance. So DementiaNI arranged some online mindfulness sessions. They also had yoga classes to help with their exercise, tailored to ability some did armchair yoga and we have established the storytelling sessions and the arts and crafts creative writing class.”

5.6 The Arts
“I think we have the power to provide support. We talk a lot about this in our strategy about what can the arts solve? I don’t think we can solve poverty. I don’t think we can solve hunger. I don't think we can solve mental ill health. But what we can do is alleviate some of the feelings that come with that and provide a sort of escape or a support.” (Artist 2)

5.6.1 The importance of the arts
In the tumultuous environment created by the fear, uncertainty, and COVID-19 regulations a constant refrain from interviewees was the need for art for art’s
sake and for the pure pleasure that it can bring. Family Carer two used music as a conduit for communication when visiting his brother who has dementia:

“He’s a huge Glen Campbell fan. We chat a lot about that and we would sing Wichita Lineman and a few of his other tunes.”

The artists had all worked with the Arts and Older People Programme and had witnessed the transformational power of the arts in people with dementia and others. Passionate about the power of the arts to enrich lives the artists argued for people’s right to have access to artistic resources and to be able to enjoy them.

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“Treat people in a humane and age-appropriate way. Saying, here's a great resource, have good craic. That's all you need to be doing. It doesn't need to be a profound life changing impact.” (Artist 2)

There was universal acceptance of the arts as a positive thing and recognition that the arts were helpful in promoting communication. Nevertheless, in practice the arts were viewed as something that happened if there was ‘time’ but as illustrated in the interview extract (right) it was clear that artistic based practice was a casualty of COVID-19 and all but disappeared in residential homes. Where the arts were used, it would appear to have been as a means to an end; to distract or occupy residents, rather than as an end in itself and simply as a source of pleasure.

To their credit the care workers were intuitively using music to help occupy and relax residents with dementia during periods of enforced isolation:

“We would have had a wee radio and played CDs and you would have sang with them. And some of them love to sing. I haven’t a note in my head sure but like it worked. You would have sang different wee songs and they would have sung a way with you. They maybe would have dozed off to sleep and then you would read wee bits out of the paper to them, and you know, just different things. Sometimes it's not easy, like, you know, trying to keep them isolated.”

(Care Assistant 1)

People with dementia can tend to wander into different areas and other people’s rooms. This behaviour was deemed high risk for two reasons. Firstly, the increased likelihood of falls in someone who is highly active. Secondly,
control of COVID-19 relies on strict isolation of people who test positive and their close contacts. Singing, music and doll therapy were used as tools to distract and occupy people with dementia during periods of isolation. Other residents who were not cognitively impaired, more sedentary, or bedbound were less likely to receive the one-to-one arts-based interventions.

“There are some songs, of course, there's always an effort made, but only when staff have a bit of time. But the people, of course, who are more bed bound they lost out because you had to try keep the dementia people occupied. Those who are quite mobile. They are very high risk of falls. They are at a very high risk of going into other people's rooms.” (Nurse)

The 80-year-old woman related the experience of her friend who is living in residential care:

“...she doesn't watch television and she doesn't read so she said the day was very long, and they are not allowed to mix she was just very, very lonely.”

This experience was echoed in descriptions from CHASNI who emphasized the importance of the arts and music in improving quality of life. Drawing on the experience of members across NI the ‘feel good’ factor of seeing videos of their loved one enjoying a bespoke playlist was highlighted:

“If a loved one gets the video, a 30 second video, or Daddy is listening to ABBA, and you see that recognition in his eyes, or you see his lips move, where he tries. He knows that music. And you can see it very clearly, especially in those with cognitive impairment. That recognition, you know it immediately. It brings a smile to see daddy smiling and you’re just thinking, ‘oh, bless them. Just look at him, he just loves it’. There was however recognition that implementation of arts-based activity was very reliant on the volition of individual carers: “We've had families that have sent in paints and jigsaw puzzles. But all of that sort of stuff takes the initiative of a carer within the home to be able to deliver.”

Drawing on decades of experience working with older people and in residential care settings Artist three understood the power of the arts to alleviate isolation and loneliness. From this position of confidence, he challenged the notion of lack of money and resources being the barrier. Arguing instead that it was absence of information and lack of knowledge about what was possible and what had worked elsewhere:

“Because there are learnings, there are things people have done, wonderful things on small budgets, but we just don’t know about.”
The DementiaNI empowerment officer champions the arts at every opportunity. It was not always so, and she confessed to initially having feelings of scepticism about the benefits of the arts for people with dementia. Having witnessed the benefits in cognitive functioning and overall wellbeing she now characterises the arts as ‘therapeutic’ and very beneficial for DementiaNI members through pandemic.

“At first I was a bit wary of how much of the arts we would integrate into our programme ... But I've actually realised that being involved in the arts, is very therapeutic for the members. It has been of great benefit to the members over the past year. Having an activity to be part of and being able to produce something physical and from home can be very beneficial. Because it's keeping the DementiaNI member engaged and they're actually having something physical to remind them of some of their time going through the COVID pandemic.” For example: “we’re running a quilting and creative writing project ...They're using a range of methods and different types of arts to design a simple piece of artwork to reflect their life and personality. So, this will be something physical that they will have by the end.”

Working in both residential care and in the community Care Assistant three had a broad and rich understanding of older people and was very conscious of the importance of the arts in alleviating isolation. She frequently sings along with clients during her visits.

“Most of them get a lot of company from the television or the radio, some of them some of them actually love to hear you singing, you know. They’d say, ‘So what's that wee song you're singing?’ and I would tell them, and they'd say, ‘oh I don’t know that one’ or they would start things off and we’d would start singing along together”.

Working through the pandemic Care Assistant three was acutely aware of the negative impact of the social isolation contained in COVID-19 restrictions on the wellbeing of her clients. To illustrate her point she gave the example of a 95-year-old woman whom she cares for:

“She is a lady who loved to get out. She would have had social nights out. She would have gone to knit and natter once a week. She would have gone to women's institute, dinners and wee things like that. She went every Saturday to get her hair done. And she is cracking up. I feel so sorry for her. She's in her nineties. She's 95. She's just kept youngish in mind if you know what I mean because she has those interests. She loved knit and natter and she can't get
there and she can't go anywhere. She can't go to church. She can't go to the hairdresser. She can't go anywhere.”

A poignantly beautiful story shared by the nurse illustrated the transformative power of music in the final days and hours of a resident’s life. The story relates to a gentleman aged in his nineties. Recently admitted to the home, terminally ill his condition deteriorated rapidly, and his family was permitted to sit with him.

“He was a very musical man, you know. He was a music teacher so at least we were able to play some classical music. He was a very good classical musician. That was the nice thing because when his son came, we were able to get a background. Like just you know what his father did. And it turned out that he was a very good musician. He had performed in the Ulster Hall and stuff. He had a wee TV in his room, so we put on radio three for him so that he always had company in the room.”

The story above also serves to illuminate the importance of life story and knowing a resident’s history. A chance encounter with the son revealed the successful career in classical music. Seeing residents as individuals with past lives, experiences, skills, likes, and dislikes is at the core of life story. Drawing on this personalised approached to care CHASNI was vociferous in the call for arts-based activities to be written into care plans and to be part of everyday life for residents. Characterized as currently being:

“...left to initiative of care workers. It's not something that's written into the daily living within a care home. It's not. It should be. It should be up there with at one o'clock the medication round happens and two o'clock lunch happens and at four o'clock the music session happens and at six o'clock supper happens. It should be written in. But it's not.”

5.6.2 Activity co-ordinator

“There’s an activities co-ordinator. They are very enthusiastic people, extremely enthusiastic people, always a smile on their face. They would be very into the arts to make people feel included. Monday through Friday, there are activities. The activities will take different forms, like there might be exercise one day and there would be a creative activity the next day. And there might be music because a lot of the dementia patients, although they may not be verbal, they sing, and they know tunes.”
Care assistant four’s characterisation (above) of activity co-ordinators was borne out in all other interviews. The activity co-ordinators were universally valued for the work. The idea that the ‘arts’ was their area was something widely believed to be true. The notion of a dynamic weekly activity schedule was something that largely belonged in a pre-COVID world. Although restrictions eased in some residential settings the easing did not apply universally, nor did it apply to all residents. As a result, daily group activities did not happen in the main.

For all their popularity activity co-ordinators are, however, thin on the ground:

“We only have one activity co-ordinator, and there's about 56 to 60 people in our home. The young woman is run ragged anyway. Even before COVID. So, you can imagine she has the whole home to spread herself between all those people. (Nurse).

One activity co-ordinator per home seemed to be the norm:

“The AC comes in and she does stuff for them and their nails and sings to them. She would try to get round everybody. If she doesn’t get to one today. She would try to get down tomorrow to get round everybody.” (Care Assistant 1).

Staffing pressures with residential settings during COVID-19 and isolation of residents in their rooms clearly presented challenges for the activity co-ordinating service. It is impossible to imagine one person doing anything meaningful with 40 or 60 residents in a 37.5 hour each week. Service demands and staff shortages meant that activity co-ordinators were often required to help with hands on care. CHASNI identified this fact as a major concern:

“We were hearing a lot of stories of providers redeploying activities coordinators. So, the activity coordinator was taken off her role. Instead, she was the person that potentially managed the FaceTime calls or the phone calls to the daughter on the outside. But we challenged it and said, ‘you know, surely given the fact that there's isolation more so now than ever, surely the role of your activities coordinator will be more important, and their job would be absolutely imperative to keep stimulation going and keeping activity going within the home’.

CHASNI’s depiction of the vital importance of activity co-ordinator and advocacy for development of the role was echoed by others:
“I think more investment should be put into care homes. To have a dedicated person whereby they could be there on a full-time basis. Looking at different activities, visual arts, music, storytelling, reminiscence, work…” (Artist 3).

5.6.3 Artists

“I remember being in work on, I think the week before we went into full lockdown. And, you know, I’ve got to say even at that stage, I don’t think we were fully aware of the extent of what was going to happen. It was really overnight. All of a sudden, we were thrown into working from the house, all activity ceased. All performances. All of my workshops.” (Artist 1)

The crushing and devastating impact of COVID-19 on the NI Arts Sector was apparent. Each of the artists shared stories about how difficult the past twelve months have been and it was obvious that talented people and capacity have been lost to the sector.

“I've lost wonderful artists because they had to give up their art forms and go and get other jobs, which is really sad, really talented artists.” (Artist 1)

The government funded furlough scheme provided a lifeline for some artists but extended periods out of work was testing:

“We were furloughed for nearly nine months this year. So that was a long time, and like everyone else. We went through, well I went through waves of, you know, trying to do positive things.” (Artist 3).

“All my stuff was very much face to face based on traditional theatre work, whether it was visual drama, music. I’ve got to say it was just overnight for us having to learn how to go about delivering our stuff online and what would work. So, we tried different combinations of private Facebook pages. Zoom, which doesn't work for everything, maybe because we weren't as confident at the start. It is working better now. We tried to use as many different platforms as we could so that we could engage with as many people.” (Artist 1)

Significantly all the interviewees commented on how much they had enjoyed and appreciated participating in the interview. They welcomed the opportunity to tell their story and reflect on the year gone by. For the artists, the interview seemed to have even greater significance. At a very dark and difficult time in the arts industry the interview enabled them to reflect on the contribution and potential of the arts:
“It’s been really lovely to be able to chat these things through. I think when you’re in the midst of it, you don’t quite understand the role that it plays or the impact, you know, especially with what’s been going on in the arts industry. It’s been decimated. It’s difficult to sometimes lift your head up and think, oh, actually, this has been really useful. (Artist 2)

The artists all had clear visions of work that needed to be done. Although all proposals were influenced by COVID-19 only one is focused, specifically on the pandemic. Artist one’s idea is reflective of her deep involvement with residential homes prior to the pandemic and the relationships with people living and working there:

“I want to go in and work with them as a family. I want the staff involved. I want to collect all their stories. I want them to share their experiences. I think it’s really important that it’s their experiences of the pandemic. Of living together through a pandemic, of becoming that family, you know. I think it’s important that their voices are heard too, because without these carers, we won’t have a place for these older people to be cared for.”

More abstract in design Artist three’s project draws on the enhanced significance that ‘rooms’ have taken on during lockdown and periods of enforced isolation:

“Choosing a room in your house and having an articulation around sort of a relationship with that room in the room with anthropomorphised person in the room.” (Artist 3).

COVID-19 shone a light on inequality in our society and the burden of ill-health and discrimination experienced by black and minority ethnic groups. It is against this backdrop and the changing demographic of NI that Artist two is strategizing:

“I think we’re starting to look at more intercultural focuses and how we can be more inclusive and diverse as an organisation." (Artist 2)

The artists were conscious that their ideas, aspirations, and proposals were dependent on supportive policy, funding, and leadership. COVID-19 had exposed the deficits and weakness in current infrastructure:

“Better heads than mine need to be sitting around that socially distanced table or the dreaded zoom and having a chat about the strategic planning of this... Because I think there are infrastructure issues that exist, that are causing problems for artists delivering and settings.” (Artist 3).
Flexible and responsive funders were deemed to be crucial in ensuring responsive and innovative arts-based programme of work. Artist two shared her very positive experience with a funder based in England to highlight the crucial role that funders have in making a programme successful:

“The immediacy of being able to contact a person and just to say listen, we’re having a real issue here with X, do you think we could do Y? Does it sound OK? And having normal conversations ... with just normal people who would have an open, honest conversation with you, where you don’t feel that you have to justify every decision. ... You can move lines around without them having expectations on the numbers that you have to meet. Without this approach we would not have been able to continue. We might have had to give the money back.”

6. Discussion

“We are nothing unless we have wonderful artists.” (Artist 1)

Social isolation has long been recognised as a major public health issue. The evidence base is clear, social isolation is associated with higher rates of all-cause mortality. (Holt- Lundstad, 2018). The pandemic has put the negative impact of social isolation centre stage, with commentators (Wu, 2020; O’Sullivan et al., 2021) arguing that the global experience of isolation has created a society more inclined and open to the need for policy supportive of social inclusion. 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 ACNI has been at the vanguard of this movement in Northern Ireland and across the UK arts sector. Working with its partners the Baring Foundation and the Public Health Agency through Arts and Older People (AOP) the ACNI was set to embark on a radical new programme of work in 2020 to make the arts accessible to people living in residential care. The arrival of Coronavirus COVID-19 delayed that work. As we prepare to enter the recovery phase of the pandemic the AOP programme and the Artistic Community in NI is well placed to make an important contribution.

Drawing on interviews with 12 participants the study serves to shine a light on the harsh reality of life for the men and women living and working in our residential care settings and the toll that it took on family members. The study echoes existing research (Barguilla et al. 2020; Cohen et al. 2020) to reveal deterioration in physical and cognitive wellbeing. It has yielded brutal images of people scrambling to see a parent or spouse through windows; of interactions
mediated through face masks, visors, aprons, and gloves; of curtains being closed to keep the world away; of health care workers emotional and exhausted from caring for people with dementia and others who through isolation and loneliness lost the will to live.

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

The beauty of the case study approach and the qualitative analysis is the opportunity to identify unanticipated outcomes. One such finding was the pivotal role that environmental factors have on supporting and promoting social contact. 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 family. 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 upmost importance that measures be put in place to ensure that residential care settings can accommodate 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 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. Evaluation of how the room in which a person is being cared for promotes dignity and right to social inclusion should be part of every care plan.

The importance of seeing the person, knowing their life stories and their interests is essential in the promotion of dignity. Life story work should be an integral part of care packages. 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. Artists have unique skills and an array of gentle tools proven to be effective in eliciting and celebrating life stories. These skills could be harnessed to great effect in advancing care, developing practice and promoting dignity for people with dementia and those living in residential care.

Research reveals that understanding of dementia and skilled staff is 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 through the study. 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 care workers frequently turned intuitively to the arts to help soothe an agitated resident or to keep them occupied during unending periods of isolation. It was however evident that they had not received specific training and education that would help their understanding. “But it’s hard. It requires a lot more patience than what I thought it would require, especially in the dementia ward.” (Care Assistant 4). 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.

The study draws on experiences in over 20 different residential care settings across NI. It is evident that where hitherto there had been some focus on arts-based activity this had all but disappeared during the pandemic. Activity coordinators were either redeployed into the core care team to help deliver hands on care, or they were stretched to the point that one can only but question the value of and satisfaction in their work. One person working with 30 or 40 residents is not realistic when each resident is in solitary isolation and many of them have dementia. That staffing levels in residential care have at times been critically low during the past year is without dispute. Faced with the dilemma of attending to the most basic needs of helping people to wash, eat and use the bathroom or enriching lives through access to and the arts; the former naturally took precedence. Ironically during the COVID-19 pandemic the artistic community was amongst the worst hit business sector in Northern Ireland. 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 spare capacity within 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 people with dementia, carers, and other isolated older people. Storytelling, singing, visual arts and musical performances are some of the programmes, which are currently available. DementiaNI members across NI 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 and awareness raising about the benefits of the arts in promoting health and wellbeing and in training 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 recouperation 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 affected by 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.

Due to COVID-19 regulations it was not possible to visit residential care settings during this study. Nor was it possible to work directly with residents due to issues related to consent and ethical questions associated with discussion about loneliness and isolation at this time. These stories remain to be told and
it is important that they are captured. The arts provide a powerful and gentle vehicle to explore and document the personal experiences of residents. There would also be great value in collecting experiences of their families and residential care workers, both groups have also experienced huge trauma and loss throughout the COVID-19 pandemic. Learning from this work would help inform and shape future residential services in a way that promotes social inclusion and dignity for all.

7. Recommendations

As the ACNI and partners PHA and Baring Foundation prepare for the next phase of the AOP there are four recommendations worthy of consideration.

1. Promote and encourage the use of arts-based activity within residential care setting. This could be realised through raising awareness of the benefits of the arts in promoting health and wellbeing. Activity co-ordinators have a key role to play in making this happen. Investment in recruitment, training, and ongoing capacity development for activity co-ordinators would help elevate their position and ability to make impact. Embedding Arts based activity within individual care plans would serve to ensure that activities and interventions are treated as an essential part of a person’s daily routine and tailored to the needs, interests, and abilities of each resident/client. The AOP programme is well placed to support training for activity co-ordinators and to foster partnership working between residential care settings and artists.

2. Provide support and encouragement for artists to become involved with residential settings and assist with the recovery phase of the pandemic. Drawing on experience with the AOP the artistic community in NI is well placed to help design and implement initiatives to promote social inclusion and combat loneliness. Inclusion of simple evaluation methodologies would help enhance the visibility of the programme’s impact.

3. Funding of arts-based initiatives directed at people with dementia and older people living in their own homes or supported living accommodation. Despite the successful vaccination programme, social distance measures are likely to remain in place and due to their age older people remain higher risk to complications of coronavirus. Consequently, all older people and those affected by dementia are likely to remain high risk of the negative impact of social isolation. Finding
innovative ways to engage with these groups is vital in promoting health, dignity and wellbeing.

4. A showcase event or events to highlight the work of the AOP through the pandemic. Since January 2021, the AOP has been proactive in making the arts accessible to people with dementia and socially isolated older people. Twelve diverse and innovative programmes have been funded, including dance, music, song writing, and storytelling. These initiatives have exploited the use of digital media and online tools. Some of the work has been with people in residential care and some with people isolating in their own home. It is vital that this work is given profile to demonstrate what is possible and showcase events would sit well with the advocacy remit of the AOP.

Some of the findings in this study point to recommendations that are outside the remit of the AOP and outside the jurisdiction of the ACNI and the Department for Communities. It would however be remiss not to flag these factors for attention by other agencies including the Department of Health, Department of Finance, the Regulation and Quality Improvement Authority (RQIA) and the Commissioner for the Older People in NI (COPNI). Chief amongst the extraneous recommendations are (i) universal and swift roll out of the care partner scheme across all residential care settings; (ii) investment in infrastructure, technology, and training to combat the digital divide; (iii) assessment of how the physical environment in all care settings promote dignity and social inclusion, (iv) dementia awareness training for all staff who are working with people who have dementia and (v) rigorous implementation of RQIA care standard 10 “Memory, life story work and reminiscence are used as part of the process of effective engagement and activity for residents.” (RQIA, 2015)
References


Chamberlain, S., Duggleby, W., Teaster, P. and Estabrooks, C. (2020) Characteristics of Socially Isolated Residents in Long-Term Care: A Retrospective Cohort Study. *Gerontology & Geriatric Medicine* October (6)1-10


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1 The image on the cover ‘Connection’ is an acrylic by Portrush based artist Gaelle Berthelot and is part of a private collection in France. For more information about Berthelot see http://www.causewayart.com/berthelot/index.html