

Voice to Voiceless, Struggle from Within and a Relevant Catalyst for Change

Tina Leonard

I'm watching a recording of an online gathering of the Dementia Carers Campaign Network (DCCN) in November 2020, to review the work that was Marie Brett's *Yes, But Do You Care?* in progress. Members, all existing or former family carers of people living with dementia, open up about what the experience of collaborating on this art project was like. "When it started in 2019, I was sceptical" admits Ray Cregan, "I had thought - we are crying out for services and supports and money is being spent on this. Is it really relevant?" Other members admit to initial scepticism too. But over the course of the two-year process their views have changed. "If there is any other way of looking at what we are facing and bringing it to the public, it has to help, it has to make a difference," says Susan Crampton, seeing the potential for awareness raising in the work. Ultimately Ray found the process "incredibly cathartic" due to the "releasing of inner things". "I would encourage more people to be involved in this kind of work," he says.

Watching, I'm struck by how powerful a gift it is, to explore and express difficult experiences and emotions and to have those reflected back to you and to others through an artwork. Art can give voice to the voiceless, to the marginalised and the unseen. This is what Marie Brett has achieved with *Yes, But Do You Care?* Art can be a catalyst for change; change in understanding and then action, within ourselves and then in the wider society.

There are 64,000 people living with dementia in Ireland and many will live with or be supported by family carers. Over 180,000 people in Ireland are currently, or have been, carers for a family member or partner with dementia, with many more providing support and care in other ways. It's a large community of people, and often a hidden one. Yet family carers are providing a crucial service, not only to their loved one but to us all. Over half the total cost of providing dementia care in Ireland is borne by family carers. It is estimated that amounts to €807 million every year.

Family carer stress and ill-health is known, acknowledged and described well in research studies. That family carers are often isolated and under-supported has never been more evident than in the findings of three reports produced and published by The Alzheimer Society of Ireland (The ASI) in 2020-21 on the impact of Covid19 on dementia. "We're in a permanent lockdown anyway," one carer said, as immense stress, burnout and anxiety was reported.

Marie Brett had previously worked with The ASI on *E.gress*, a filmic art piece exploring ambiguous loss theory in relation to the lived experience of dementia. That work process had involved collaboration with people living with dementia, ASI day centre staff and family carers and it built trust. Marie had toured the film nationally and achieved considerable public engagement.

Then a new piece of legislation came into her view. It became law at the very end of 2015 but is yet to be fully implemented. The Assisted Decision Making (Capacity) Act assumes that decision making capacity exists unless otherwise proven and it outlines assisted decision-making processes. Adopting a rights-based approach is brilliant, not to mention necessary, so that Ireland complies with the United Nations Convention on the Rights of People with Disabilities. It is complex legislation. What

impact does the right to make a bad decision have, for example, and what will it mean in practice to the lives of family carers and to their rights? Exploring this is the motivation behind *Yes, But Do You Care?*

What followed has been a two-year process that is creative, reflective, adaptive, and inclusive. Marie led the initial research phase while she was an invited artist-in-residence at IMMA. Assisted by The ASI, she met DCCN members, dementia specialists at the Mercer Institute for Successful Ageing in St James hospital, scholars at the Global Brain Health Institute at Trinity College Dublin and human rights and law scholars at the National University of Ireland Galway.

In partnership with The ASI, funding was received from the Arts Council via Create, Dublin City Council and Dublin Dance Festival and so began a series of in-person meetings and workshops with DCCN members held in Dublin, Limerick and Cork. These were facilitated by the ASI's Advocacy, Engagement and Participation Officer Laura Reid, who co-ordinates and develops the DCCN's work. Marie distilled all the material from these sessions for dancer and choreographer Philip Connaughton, a partner on the project, to create responses in dance to people's stories and testimony. Marie worked with a voice coach to choose voiceover actors to read carers' stories.

At this point in time everyone and everything moved online. Initial plans for a live performance event were revised and further funding for this new re-imagined phase was secured from Bank of Ireland and Business to Arts 'Begin Together' programme. In August 2020 a window of lockdown opened and IMMA hosted live public work-in-progress showings in the People's Pavilion. DCCN members kept feeding into the developing work. An advisory team of experts of a variety of disciplines stayed involved. Filming took place at IMMA inside their residential artist's house and grounds while strictly adhering to social distancing guidelines.

And so, while still in lockdown, a live staged installation event was filmed in a large, empty warehouse space. There is live dance and spoken word with projected photographic stills, light, sound and sculptural forms, all directed by Marie. Streamed online for two weeks in April 2021 by both IMMA and The ASI and including online public conversations, the art piece is free to view online and the development of contextual materials is ongoing.

Yes, But Do You Care? is a fearless production and the process of its making gives it immeasurable value. Collaboration and inclusion make it representative and real, and it gives viewers a connection and emotive response that would not otherwise occur. It gives this work power. You will hear, see and feel the challenges of decision making that come with caring through it. Philip Connaughton can quite literally embody an experience or emotion in his dance. DCCN member Máire Anne Doyle describes Philip's dance as clearly showing "the struggle from within". "The demon guilt can suffocate you," she says describing how the responsibility and the guilt of decision making can be overwhelming. "You're screaming inside permanently. Philip's movement really does link with the words we expressed." This is art linking the private to the public.

Reimagining *Yes, But Do You Care?* to be presented online will mean a new and wider audience can be found now and in the future. There are so many ways to connect with this piece and so there is surely an audience beyond the traditional art audience. Family carers can find in it a reflection of their own emotions and may experience catharsis themselves in turn as DCCN members did. Health practitioners, human rights lawyers, researchers and advocates will all find something here that impacts positively on their work and at the very least enriches it by providing a different perspective to the one they are most familiar with.

“I was keeping down emotions that were perfectly normal, but nobody spoke about them,” Máire Ann Doyle of the DCCN said. *Yes, But Do You Care?* brings these emotions out of the shadows. The Alzheimer Society of Ireland is proud to have played a role in this work and congratulates Marie Brett on her achievement and on her tenacity in keeping the work going through so much societal upheaval.

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