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‘Arts and culture as part of a framework of hope for dementia’.

I am delighted to be here this morning. Just listening to the other speakers today I immediately feel among friends. My brief today is to talk about art and culture as part of the framework of hope for dementia. I am psychiatrist, and I have worked for the last three - five years with people with dementia. Just a couple of reflections before I start my talk:

After working with people with dementia, it is impossible to overestimate the feeling of anxiety and fear around the time of disclosure for diagnosis. It is important that you must empathise with individuals, but it is also important the person must leave room with a sense of hope. Hope is so important in terms of adaptation and living well with dementia.

The second reflection is that I have a feeling over last the 35 years in my profession, I have been working in a silo. I think over the last number of years my eyes have been opened in terms of breaking down the professional silos and working together. Working with artists and other professionals is really crucial in changing the narrative and really making the difference to people with dementia. I think it resonates with much that has been said this morning.

To reflect on this issue of fear, fear being the great enemy of hope. Dementia is feared particularly in those over 50. Many fear dementias more than they do cancer or even strokes. We conducted a survey a number of years ago as part of the Irish Dementia Awareness

Campaign, looking at attitudes and knowledge of dementia of the general public, *Public knowledge and understanding of dementia- evidence from a national survey in Ireland* (2017). We found that four out of five people

National survey in Ireland: what people say

4 /5 would be scared or anxious

1/3 wouldn't want their friends or family to know

1/4 people delay seeking help

Fear and stigma surrounding dementia are major issues for the general public

Glynn et al. Age & Ageing 2017

said that they would be scared or anxious if they were given a diagnosis of dementia. One in three wouldn't want their families or friends to know. One in four would delay seeking help if they thought they might be developing dementia. There is a lot of fear out there in terms of a dementia diagnosis; and there is a lot of stigma, which is an ongoing issue for the general public. Professional attitudes also abound with stigma. There is a sense that there is little or nothing which can be done, a sense of therapeutic nihilism, perceived lack of treatment options, focus on safety and risk, and of course this creates significant barriers in terms of people with dementia being included in activities, and being able to participate in society.

All in all, if you read the newspapers - this is a word cloud of descriptions of dementia - you get the sense that a lot of people feel that dementia is a diagnosis without hope. I think this is fake news and a false narrative. There is a lot we can do in terms of the power and the value of participation and engagement in arts.



I wanted to speak about hope. Hope being a powerful antidote to the fear and stigma around dementia. The construct of hope is interesting. Hope is both an emotion and a way of thinking, they are cognitive and emotional aspects to hope. In the context of a disclosure of a diagnosis to a person with dementia, the emotional aspect of hope is around a sense of trust, care, and empathy. But the thinking part of hope relates to setting goals, being motivated, and creating pathways for action. Both aspects of hope are really

Hope is an emotion *and* a way of thinking



Hope is crucial in the face of uncertainty

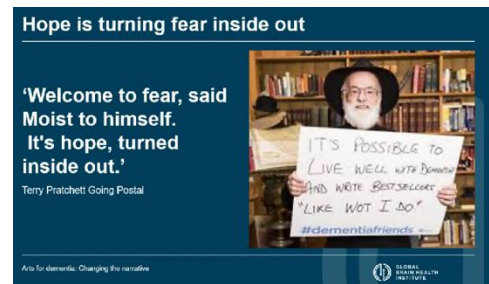
important, both the emotional and the cognitive aspects for hope in terms of helping the person adapt and live well with dementia. Hope is really crucial in the face of uncertainty. There is nothing more uncertain than around the time of a diagnosis of

a dementia. Hope is really important in the context of that disclosure, around that time of diagnosis. It is critical to instil hope around the time of diagnosis, and to focus on what can be done with goals, actions and pathways. This is really crucial in terms of countering negative reactions and behaviours that can occur around the time of diagnosis. If there is not hope, it is much more likely that they will develop anxiety and depression, and also withdraw from activities.

'Welcome to fear . . . It is hope turned inside out.'

You will recognise Terry Pratchett here who had a rare form of Alzheimer's disease.

Initially, there was a lot of anger and fear, he felt it was like a diagnosis of cancer 40 years ago. But Terry found a way to deal with it. He found pathways, he found goals, he developed a sense of agency about how he was going to deal with this. In the sign he is holding he said, 'It is possible to live well with dementia and write bestsellers "Like wot I do."' I also love this quote from one of his characters in his book, *Going Postal*, 'Welcome to fear. It is hope turned inside out.' I have just turned this round, saying that hope is actually turning fear inside out.



This is what we want to do. I think this is what the arts can do for people with dementia. It offers opportunity for hope. It provides a pathway to hope. It can provide agency, it can provide the way, but also the right emotion. We have heard how the arts can improve brain health. The arts can promote equity and inclusion for people with dementia. The arts can decrease anxiety and improve a sense of wellbeing and mood. But there is a gap between where we are now in terms of what we know works, and the gap across to policy in terms of social prescribing and moving this very strongly into policy. The UK is ahead in this regard, many parts of the world are not moving with the same sense of rapidity. There is this major gap still between where we are, and where we want to be in terms of policy and practice, and arts and dementia.

Here are my thoughts on bridging this gap. One area, one possible solution, is the whole area of leadership. Leading for change in this regard. All of us want change, very few of us find it easy to change. Finding leaders to lead change is difficult. What we need is a lot more leaders in the area of arts and dementia. We need to break down professional silos. People like me have been working in silos for too long, we need to work together across disciplines. Science, arts and medicine need to work together. This will allow us to create a much greater awareness about the value and benefits of arts for people with dementia. It is really important that we build the effectiveness and the evidence base, because that's what gets the policy makers attention.

This is what will allow us to improve the lives of people living with dementia.

¹ Terry Pratchett, 2004, *Going Postal*.

This brings me to The Global Brain Health Institute (GBHI), where I work. The GBHI was founded in 2015 and is dedicated to protecting world's population from threats to brain health and dementia. It was founded by a generous gift from the Atlantic Philanthropies, and the founding sites are at University of California, San Francisco, and Trinity College Dublin.

What does GBHI do? One of its main goals is to train the next generation of leaders in the area of brain health and dementia prevention. We call these the Atlantic Fellows for Equity in Brain Health. What is interesting about these fellows is that they come from a mix of disciplines, professions and backgrounds. They have different skill sets and varying perspectives and approaches. We believe that it is important to break down those professional silos, but also, we need this interdisciplinary and interprofessional mix to arrive at new solutions. Core to this mix of disciplines are artists. They learn and train together, then we have an alumni programme so that they network for life.

At GBHI we very much embrace the arts because we believe that it facilitates connections and participation for people with dementia. It can help us understand and provide meaning for the experience of dementia. It promotes inclusion and equity for people with dementia. Through narrative and storytelling, it can help transform perceptions and reduce stigma. It can help raise public awareness and act as advocacy for people with dementia, and it can very much improve dementia care and helps maintain brain health in people who have dementia, it helps stabilise those trajectories.

You heard earlier from Dominic Campbell, who is a Senior Atlantic Fellow at the GBHI, and this is a framework that he has developed for how the arts can improve the lives of people with dementia. You can see a number of different pockets, and then actions that form from these pockets of activities. So, connection, meaning, research, equity and promotion.






These are all areas of activity which result in actions like increased engagement, understanding, exploration, transformation and advocacy in the area of arts, brain health and dementia.

How the arts can improve the lives of people with dementia

Arts, Creativity & Connection	Arts, Creativity & Meaning	Arts, Creativity & Research	Arts, Creativity & Equity	Arts, Creativity & Promotion
Engage	Understand	Explore	Transform	Advocate

A number of our fellows are implementing and changing the landscape for dementia. Magda Kaczmarek is a dance therapist who engages with people through dance. Karen Meenan is a social entrepreneur who engage with people with dementia through co-creation and reminiscence, and Grainne Hope who is a professional cellist who performs music for people living with dementia in care homes. Alex Kornhuber is an artist from Peru who chronicles the lives of people who are ageing with dementia through photography. There are a number of examples where our fellows are transforming and changing the landscape for dementia.

Leadership in arts and dementia

-  Leaders in arts
-  Leaders in arts and dementia
-  Leaders in many disciplines that understand arts practice and arts thinking
-  Breaking down the silos: working together with other disciplines
-  Together, changing the narrative from tragedy to hope

Arts for dementia: Changing the narrative



I think there are many ways that the arts and creativity can help turn the fear and stigma of dementia inside out. The focus for us at the GBHI is around leadership, leaders in the arts and dementia, leaders from many disciplines and many professions that understand art practice and art thinking, working together, breaking down the silos, and in that way changing the narrative from tragedy to hope.

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