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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’m psychiatrist, and I’ve worked for the last thirty-five years with people with dementia.

Just a couple of reflections before I start my talk: In working with people with dementia, it is impossible to overestimate the feeling of anxiety and fear that is experienced around the time of disclosure of diagnosis. As a physician, it is important that you can empathise with the person and that they can leave the room with a sense of hope. Hope is so important in terms of adapting and living well with dementia.

The second reflection is that as a medical doctor, I have a feeling that over last the 35 years in my profession, I have been working in a silo. Over the last number of years my eyes have been opened to the importance of breaking down the professional silos and working across disciplines. Working with artists and other professionals is really crucial to changing the narrative and really making a difference to people living with dementia. This approach resonates with much with what has been said already this morning.

Reflecting on the issue of fear, fear is the great enemy of hope. Dementia is feared particularly in those over the age of 50. Many fear dementia more than they do cancer or even stroke. We conducted a survey a number of years ago as part of the Irish Dementia Awareness Campaign, looking at attitudes and knowledge of dementia in 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**

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- 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

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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 much fear out there in terms of a dementia diagnosis; and there is a lot of stigma around the diagnosis. Professional attitudes also abound with stigma. There is a belief amongst health care professionals that there is little or nothing that can be done, a sense of therapeutic nihilism, a perceived lack of treatment options, a focus on safety and risk. All of these attitudes create 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 – and here you see a word cloud of descriptions of dementia - you get the sense that many people feel that dementia is a diagnosis without hope. I believe that this is fake news and a false narrative. There is much we can offer people with dementia and in particular through participation and engagement in the arts.



I first want to speak about the concept of hope. Hope is a powerful antidote to the fear and stigma around dementia. Hope is both an emotion and a way of thinking. In the context of disclosure of a diagnosis to a person with dementia, the emotional aspect of hope is about conveying a sense of trust, care, and empathy. The thinking part of hope relates to setting goals, generating motivation, and creating pathways for action for the person. Both aspects of hope are really important in terms of helping the person adapt and live well with

### Hope is an emotion and a way of thinking



Hope is crucial in the face of uncertainty

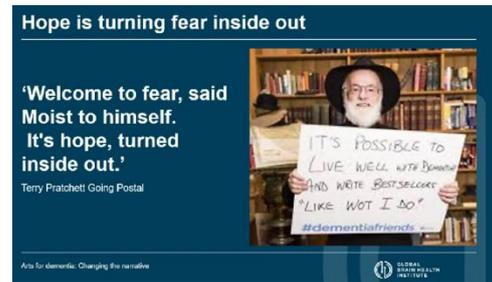
dementia. Hope is crucial in the face of uncertainty. And there is nothing more uncertain than the time of a diagnosis of a dementia. Hope is really important in the context of that disclosure of diagnosis. It is critical to instil hope around the time of diagnosis, and to focus on what can be done for the person in terms of goals, actions and pathways to counter negative reactions and behaviours that happen at the time of diagnosis. If there is no sense of hope, it is much more likely that the person will develop anxiety and depression, and also withdraw from activities.

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

You will recognise Terry Pratchett here who had a rare form of Alzheimer's disease called posterior cortical atrophy. Initially, he experienced a lot of anger and fear, he likened the diagnosis of dementia to the diagnosis of cancer 40 years ago. But Terry found a way to deal with it. He found pathways, he identified goals, he developed a sense of agency about how he was going to deal with his illness. 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 Moist, in one of Pratchett's books called *Going Postal*, 'Welcome to fear. It's hope turned inside out.'



This is what we want to do: to create hope, to turn fear inside out and this is what the arts can do for people with dementia. It offers an opportunity and a pathway for hope. It can generate agency, it can show the way, but also provide the emotional part of hope. We have heard how the arts can improve our brain health. The arts can also promote equity and inclusion for people with dementia. The arts can decrease anxiety and create a sense of wellbeing and lift mood. But there is a gap between what we know works, and policy and practice in the area of arts for dementia. The UK is ahead in this regard, but many parts of the world are not moving with the same speed and sense of urgency.

Here are my thoughts on how best to bridge this gap. One possible solution is to train more interprofessional leaders to drive change in the area of arts for dementia. Science, arts and medicine need to work together. This is what will allow us to improve the lives of people living with dementia.

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.

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<sup>1</sup> Terry Pratchett, 2004, *Going Postal*.

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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 most 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.

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 to the experience of dementia. Arts also 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 a means of advocacy for people with dementia, and it can very much improve dementia care and helps maintain brain health in people who have dementia.

### How the arts can improve the lives of people with dementia

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

You heard earlier from Dominic Campbell, who is a Senior Atlantic Fellow at the GBHI, and this is a framework that he has proposed for how the arts can improve the lives of people with dementia. There are a number of different pockets, and then actions that follow from these pockets of activities. These areas of arts activity result in actions like increased engagement, understanding, exploration, transformation and advocacy for the person with dementia.

A number of our fellows are implementing and changing the landscape for dementia through arts practice. Magda Kaczmarek is a dance therapist who engages creatively with people with dementia through dance. Karen Meenan is a social entrepreneur who works with people with dementia through co-creation and reminiscence, and Grainne Hope 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 that are ageing and living with dementia

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through his photography. These are a number of examples of how our fellows are transforming and changing the landscape for dementia in a positive way through arts and culture.

### Leadership in arts and dementia

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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



In conclusion, I believe that 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 GBHI is around leadership, creating more leaders in the arts and dementia, leaders that come from different disciplines and professions that understand arts practice and arts thinking, that are networked and work together, breaking down the silos, and in that way changing the narrative of dementia from tragedy to hope.

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