The next generation of leaders advocating for brain health

A monologist, a musician, an event producer, and an animal behaviourist are working to change how society thinks about aging and dementia. These individuals are part of the first cohort of Atlantic Fellows at the Global Brain Health Institute and are using their talents to transform the way we think about and care for elders and people with dementia. Dana Smith investigates.

The Global Brain Health Institute (GBHI) has undertaken the ambitious goal of “reducing the scale and impact of dementia” worldwide by training the next generation of leaders in brain health. Based at the University of California, San Francisco (CA, USA) and Trinity College Dublin (Dublin, Ireland), GBHI facilitates dedicated and creative individuals in addressing the wide-ranging effects of dementia through prevention research, education, and advocacy. The Atlantic Fellows training programme at GBHI—which includes artists, journalists, and entrepreneurs, as well as neuroscientists, neurologists, and psychologists—takes an inter-professional approach to disrupt conventional thinking about aging and dementia. Fellows from differing disciplines nurture and learn from each other in a unique bi-directional thought exchange, fostering innovative interventions. Four of these Fellows are working to change the narrative around dementia by sharing stories about the steps people can take to protect their brains, reframing how we think about aging, and helping patients with dementia cope through art and interpersonal connections.

Josh Kornbluth is a theatrical monologist based in San Francisco (CA, USA), who tells autobiographical tales onstage and onscreen. Kornbluth’s stories often relate to issues of social justice, and his comedic approach makes difficult and often misunderstood topics more accessible. Following the diagnosis of his step-father with Alzheimer’s disease, Kornbluth turned his attention, passion, and skill for storytelling to the subject of dementia. He is developing a one-man show based on his experiences at GBHI to educate audiences about brain health and the experiences of patients with dementia and their caregivers. Kornbluth is also helping patients and caregivers tell their own stories onstage. His objectives are twofold: shift audiences’ preconceptions about what it’s like to live with dementia, and provide patients and caregivers with a form of art therapy to express themselves, empowering them to reclaim their personal narratives. Retelling, and thereby reshaping, the narrative around a traumatic event, such as a dementia diagnosis, can change how a person perceives their experience of it. Research has shown that so-called expressive writing—writing about one’s experiences and emotions—can reduce depressive symptoms, boost working memory, and even improve physical function in patients with cancer. James Pennebaker, Professor of Psychology at the University of Texas (Austin, TX, USA) and the author of Writing to Heal thinks that “there is now a great deal of research to suggest that writing about personal upheavals can improve people’s physical and mental health.” He also thinks that narrating personal upheavals through theatrical performance might also be valuable, “to the degree that people are able to organise their thoughts around very complex personal problems.” For Kornbluth, the power comes from simply reminding these patients that they still have stories to tell. “The narrative that people feel—both the people who get the disease and the people who love them and care for them—these people feel that their life story is bifurcated or, even in a sense, that the real life ended when the symptoms or the diagnosis began,” he says. “I want to get them to communicate that their lives were not bifurcated. That this was a full life, certain things had happened, certain things had changed, but it was the same person who was experiencing this.”

For patients who have lost verbal communication skills, music can provide an alternate source of enjoyment and connection. Exposure to music can reduce blood pressure and stress hormones, and music therapy can improve behavioural and psychological symptoms of dementia. Musician Heidi Clare taps into these benefits by performing for elders and people with dementia in Marin County (CA, USA). She describes the transformative effect music can have: “When I first walk in, they’re shut down...But by the time I leave, even after just the first time I work with them, they’re changed, they’re open. And after three times of working with them, they’re rowdy!” Jessica Phillips-Silver, a cognitive neuroscientist at Georgetown University (Washington, DC, USA), explains that these energising effects are due to the ability of music—and particularly of rhythm—to activate a widespread
Dominic Campbell is leveraging the unique atmosphere of festivals to spread the gospel of brain health. For seven years, Campbell produced the Bealtaine Festival in Ireland, which celebrates the arts and creativity of elderly people. The benefits of engaging elders in the arts are well-documented. In *Ageing Artfully*, a report by The Baring Foundation (London, UK), director David Cutler writes, “In addition to the intrinsic and fundamental joys of creativity, artistic expression, and entertainment, at its simplest the benefits from work in this area can be divided along two dimensions: health—physical and mental wellbeing—and relationships—personal or immediate (family, friends, carers, staff) and societal, or broader (community development).” Campbell’s new initiative, a travelling arts festival, will continue to focus on aging. Inspired by his time at GBHI, he plans to incorporate more science into the festival acts, featuring researchers who will disseminate innovative ideas and interventions directly to the audience. “Through festivals, people enter a different kind of state. They are much more likely to try out a new thing at a festival than they are if they’re walking down an average street,” Campbell explains. He hopes that this openness will inspire people to try new foods, exercises, or hobbies that might help improve their brain health later in life in the hopes they adopt them once they return to their everyday lives.

Animal behaviourist and entrepreneur Adam Waskow joined GBHI after more than 20 years working at Guide Dogs for the Blind. He hopes that his new endeavour, Memory Dog, will do for people with dementia what Guide Dogs does so well for the blind. Spending time with animals is a generally soothing experience that can decrease stress and agitation. Animal assisted therapy has been linked to lower levels of loneliness and depression by providing social and emotional support, as well as facilitating interactions with other people. Therapy animals can also act as triggers for memories of past pets or serve as a substitute for pets that have to be left behind when a patient enters a care facility. With Memory Dog, Waskow wants to provide therapy animals to patients with dementia at different disease stage, ranging from those who still live in their own homes to full-time residents at care facilities. He thinks that therapy dogs can assist dementia patients with agitation, apathy, and compliance with medication, hydration, and hygiene. “Therapy dogs are something that are scalable and affordable, that we can teach people to use, and that we can get into a lot of places,” Waskow explains. One of the first alumni of the Atlantic Fellows programme at GBHI, Waskow is now raising funds to launch his initiative. The money will go toward building a memory dog centre in Marin County (CA, USA), and to train memory dogs for people with dementia.

Regardless of the type of intervention, the four Fellows agree that inter-personal connection is key. Narrative, music, art, and animals provide varying means to engage with elderly audiences, but the result is the same—feelings of community, empathy, joy, and purpose. Kate de Medeiros, a gerontologist at Miami University (Oxford, Ohio, USA), supports this idea. “People forget that people with dementia, regardless of type, have capacity to engage in meaningful things.” She adds that people often “overlook this very important aspect of human engagement” and that “the arts are a really good way of making that connection with people.” Through their work, the Atlantic Fellows hope to improve the lives of old individuals and those with dementia, and they strive to change society’s narrative of dementia from a loss of self to a gain of new ways to connect with others.

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