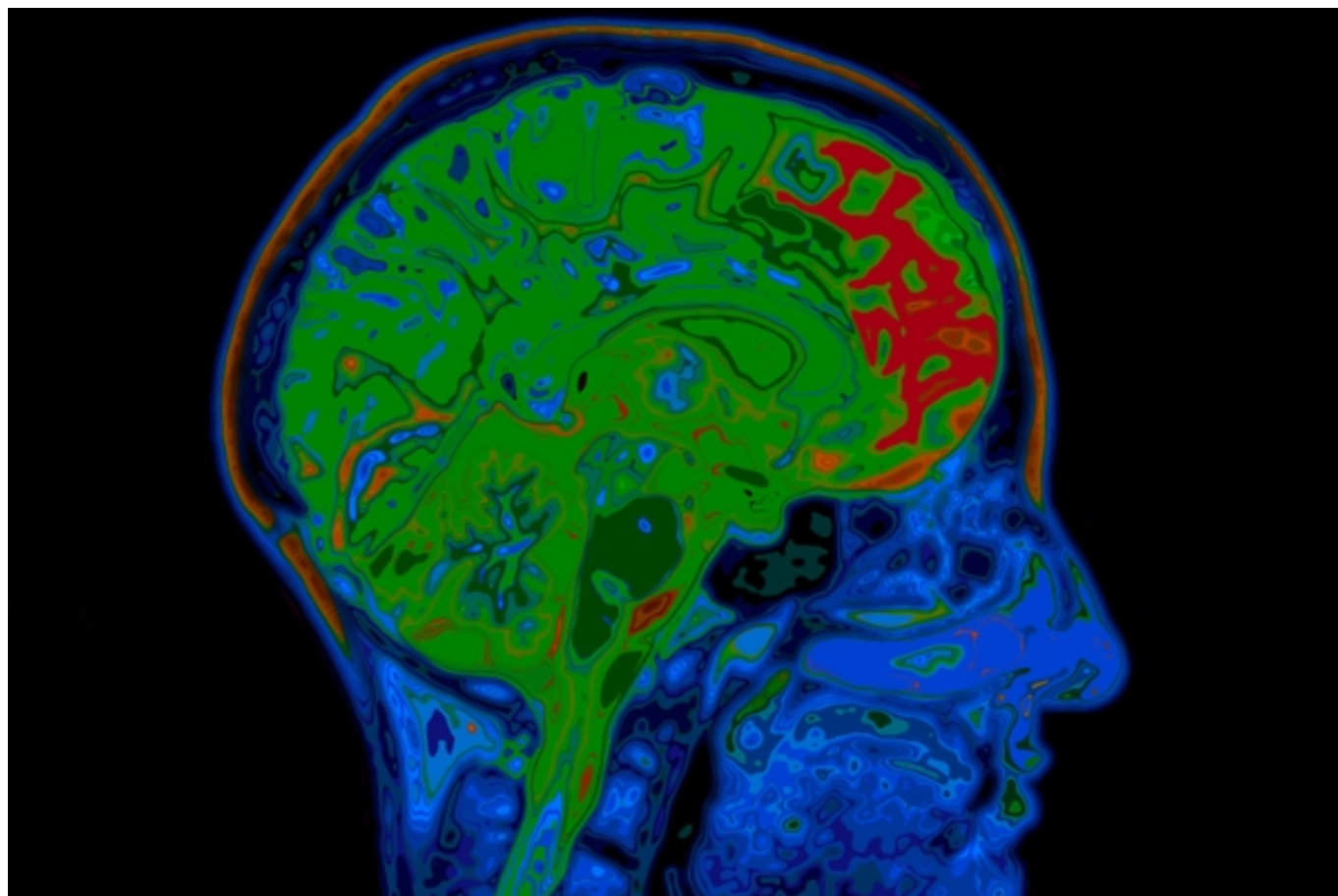

A question of how, not if: the importance of including dementia in mental health discussions

Submitted by ncd-admin on 7 novembre, 2018 - 13:34







Langue Anglais



Dementia has certainly grown in stature as a priority disease within the mental health debate, but we are still far from a widespread acknowledgement of the epidemic it is. The impact of dementia on the well-being of carers of people with dementia is also well documented but does not yet receive the attention it deserves; we need more mental health support for people with dementia and their families.

At the United Nations (UN) High Level Meeting on Non-Communicable Diseases (NCDs) in New York on 27 September this year, mental health conditions were recognised as one of the five components of the UN's '5-by-5' approach to NCDs. The resulting Political Declaration mentioned the key role of civil society organisations and the importance of working with people living with or at risk of NCDs, but there was no explicit mention of dementia. ADI's position is aligned with NCDA's [statement on 27 September](#) [1] – we feel the Declaration was lacking in key areas. With dementia affecting 50 million people worldwide, and with 152 million people forecast to be living with dementia by 2050 – mostly living in lower and middle-income countries (LMICs) – this is extremely concerning. We need to talk about dementia.

Merging dementia and mental health

The merging of discussions on dementia, cognitive impairment and mental health are both advantageous and potentially confounding. There are indeed some overlaps in symptoms and similarities between the experiences of people with dementia and those with mental health conditions. For instance, both groups often lack access to services and support, face stigma and are denied their human rights.[1] They are also united by an increasing recognition that addressing risk factors and psychosocial determinants of health can contribute to a holistic approach to rather than a purely medicalised treatment model.

This merging could, however, lead to the erasure of dementia within high-level policy discussions. It must be recognised that neurological disorders such as dementia are a crucial part of the mental health discussion and dementia has had a long and active global advocacy community.

One of the most tangible links between dementia and mental health is the mental health of carers. Our recent report on [Global estimates of informal care](#) [2] revealed that 71% of informal care is undertaken by women. Women report more symptoms of depression, anxiety and disruption of their leisure activities, and certainly for some individuals this is compounded by risks incurred through their caregiving responsibilities. Caregivers often have to reduce their hours of paid employment or eventually quit work if their caregiving responsibilities increase. This, too, can lead to social exclusion. In this way, women as caregivers have increased risk factors of dementia, especially given the links with mental health. These women face a 'triple jeopardy' in that they are discriminated against based on their sex, age and medical condition. So, in this way, it is clear how the dialogues can become merged, and how this may be preferable in some regards but not others.

Where we have been?

ADI was pleased to see specific mention of Alzheimer's Disease in the [Political Declaration on NCDs](#) [3] in 2011. However, in spite of advocacy by many, including the WHO, and the inclusion of members of ADI and DAI in the High-level Working groups leading up to the United Nations High-Level Meeting this year - dementia was not mentioned once. In this Summit's [Political Declaration](#) [4] there is a strong mention of mental health and neurological conditions as factors, but dementia did not appear explicitly.

This is disappointing given that there have been improvements in dementia science surrounding risk factors since the meeting in 2011. It is now clear that promoting healthy diet, physical activity, reduced use of alcohol and cessations of tobacco, are simple and cost-effective measures to reduce premature death and disability from all NCDs, including dementia.

Where we are now?

There has certainly been some evidence that the WHO has taken dementia seriously. In May 2017, the [Global action plan on the public health response to dementia](#) [5] was adopted, encouraging at least 75% of member countries to adopt national dementia plans by 2025. The WHO [produced some explanatory materials](#) [6] in order to engage with people living with dementia and their care partners, as well as policy makers, health and social care providers, and civil society in this important work.

I recently spoke to Kate Swaffer, CEO of our partner organisation, Dementia Alliance International (DAI), about her experience as someone living with dementia and engaging in high-level mental health policy work. I asked whether she thinks this has changed significantly in recent years. She told me that when attending the [WHO Mental Health Gap Action Programme \(mhGAP\)](#) [7] Forum in 2016, she was advised that she was the first person to physically represent

dementia at this event. In 2017, members of ADI also attended, to increase the representation of dementia. At the mhGAP Forum this year, although dementia got little mention in the general sessions, a workshop-style parallel session on dementia care pathways was organised with at least 40 participants in attendance. The workshop engaged with all sectors present on what they want to see in terms of post diagnostic support, including rehabilitation and palliative care. To us, this signifies that there has been some progress, but we are still fighting to get dementia explicitly recognised.

Kate put it succinctly:

"Although it comes under the umbrella of mental health at the WHO, dementia is not a mental illness, and as a non-communicable disease affecting 50 million people currently, it deserves much more attention; it cannot be sufficiently addressed simply as 'one of the NCD's'. With a new diagnosis every three seconds, and a projected 152 million by 2050, it is imperative that dementia becomes an even greater priority."

Looking to the future

More voices are better than one. ADI has been a constructive part of the [Civil Society Working Group](#) [8] and will continue to do so. We encourage countries to engage with their NCD counterparts. When this is done, it is very effective. For instance, after the NCD Alliance (NCDA) Forum in Sharjah last year, NCDA Sri Lanka stepped up and expressed interest in taking a lead in the region and acknowledged the importance of dementia – leading to the development of the Association of Southeast Asian Nations (ASEAN) and Asia Pacific NCDA branches.

But still, we need more action and less rhetoric. ADI has been involved in the '[Our Views, Our Voices](#) [9]' campaign for the past two years. More initiatives such as this, which empower people with or at risk of having NCDs, are needed.

Dementia is one of the major causes of disability and dependency among older people worldwide and a crucial part of any discussions of mental health and NCDs. The Political Declaration was severely lacking; the exclusion of an explicit mention of dementia is disconcerting. The inclusion of dementia and other NCDs within the global political agenda during this pivotal year for NCDs should have been stronger, much stronger. As advocates we will not rest until dementia is getting the attention, recognition and response it so greatly needs.

About the Author

Annie Bliss is Communications and Policy Officer for Alzheimer's Disease International (ADI) ([@alzdisint](#) [10]), the global umbrella organisation of Alzheimer associations, representing 94 organisations and in official relations with the World Health Organization (WHO) since 1996. Dementia Alliance International (DAI) is a registered charity and is the global voice of people with dementia with members in 47 countries.

[1]For more on the human rights of people living with dementia please read Dementia Alliance International's publication [The Human Rights Of People Living With Dementia: From Rhetoric To Reality](#) [11](2016).

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