

Kudos to the Dementia Action Alliance

2016 Whitepaper: “Living with Dementia –
Changing the Status Quo”

by Mary Donnelly

“I am a person.” So begins the list of values and principles of the [Dementia Action Alliance](#), a coalition of people dedicated to improving the lives of people living with dementia and supporting their families. In its 2016 whitepaper, “[Living with Dementia – Changing the Status Quo](#),” the DAA sets out its recommendations for enabling the wellbeing of persons affected by dementia, and calls for reform in two major areas: the medical community and society at large.

The report first chastises the current healthcare system for its failure to adequately address the needs of those affected by dementia. All too often, an individual diagnosed with dementia is defined solely by symptoms and stages; a dehumanizing and discouraging perspective that ignores the whole person and instead centers attention on deficits rather than capabilities.

The advances made in medicine over the last hundred years are no less than miraculous, and the work and dedication of healthcare professionals is deeply appreciated. However, although the general public looks to the medical community for advice and assistance, the majority of physicians are deplorably uneducated and uninformed about dementia beyond that of the diagnosis. Since there is no cure or even effective long-term treatment for dementia, many physicians avoid even discussing it with their patients, and may often choose not to disclose the diagnosis. Many still consider it a mental health issue, and will prescribe antipsychotic medications without understanding the differences between the two conditions.

Rather than writing off a person diagnosed with dementia as *incurable*, and therefore untreatable, the medical community should instead become a frontline resource for the person with dementia, as well as their families, to learn how to live more fully with this condition. Therefore, what is needed is a transition away from a limited model of care that is fixated on physical health, to a more holistic, integrative approach embracing all of the factors that contribute to the person’s wellbeing – a mind-body-spirit view that advocates define as **person-centered care**. This would mean having a broader understanding of all the dimensions that support an individual’s sense of wellbeing and developing an approach that is bio-psycho-social-spiritual and not solely medical. While there are many healthcare professionals who might wish to adopt such a change, it is simply not possible to achieve this type of person-centered care using our current medical models.

The second important issue of the DAA’s white paper is the public mindset, misperception, and stigma with regard to dementia and the impact that these attitudes have on the wellbeing of persons living with dementia. There exists a global devaluation of persons diagnosed with dementia, fueled by the media’s sensational and often erroneous reporting, the medical community’s demoralizing perspective, and the fear-

mongering tactics of fundraising efforts. As a result, persons diagnosed with dementia are routinely overlooked and excluded from serving on committees and advisory councils, even for those organizations whose primary focus is dementia related. Even families, sometimes within a matter of days of receiving their loved one's diagnosis, often assume that the person living with dementia is no longer able to function normally in any capacity.

This marginalization of persons living with dementia makes it impossible for them to live their lives in a positive, affirming way. As one person diagnosed with mild cognitive impairment laments, "Why do we cheer a cancer survivor but not a person living with dementia who is trying to live fully?"

What is needed is a societal overhaul, a broad paradigm shift in how we perceive dementia. Rather than seeing it as shameful or embarrassing, what if society viewed dementia as a disability – like MS or a brain injury – and then made adaptations to support a person living their life as fully and meaningfully as possible? We have made this leap in how we perceive those living with HIV and other chronic conditions. Can we do any less for those living with dementia?

Some changes are already in place, but there is much yet to be done. Some areas of healthcare, such as childbirth and cancer, have already made the conversion to a bio-psycho-social-spiritual culture of care. If we don't make the change simply out of compassion for our fellow human beings, there are financial and demographical reasons to do it, including a growing older population and the draining cost to both private and government sectors.

Living well with dementia doesn't necessarily mean as defined in the medical sense, i.e., "free of disease." Rather, it means recognizing the strengths and abilities that remain and empowering and enabling a sense of purpose, self-worth, and belonging in each person living with the condition. It is an acceptance of a chronic disability as a part of one's life without it defining one's life. As Alzheimer's advocate Brian LeBlanc says, "I have Alzheimer's but it doesn't have me."

The DAA acknowledges that some progress has been made and calls for united public efforts to eliminate stigma and discriminatory practices, to transform our healthcare system, to fund research, and above all to raise awareness for change, support, services, and care for persons living with dementia.