

“See the Person...Not the Dementia”

International Advocacy Efforts

by Robin Andrews

“See the person...not the dementia” - this is one of the heartfelt requests of a global advocacy group that lives and breathes the phrase “**why language matters.**” Dementia Alliance International is a non-profit group founded by individuals living with dementia who represent and support others living with dementia.

In January, DAI will celebrate its 2-year anniversary in an online global celebration. Determined to be a united voice of strength, membership is free and open exclusively to anyone living with dementia from any country around the world. In addition, the DAI offers a monthly blog and educational webinars that are open to anyone who wants to listen and are a great resource for learning more from those who share about how we can help improve their quality of life.

Members have made great efforts over the past two years to speak out about the **impact of words** and the effects of language on thinking and perspective of oneself. In 2014 DAI shared publicly the first comprehensive Language Guidelines created by Alzheimer’s Australia as well as an online webinar, **WORDS ABOUT WORDS: Changing the Language of Dementia** featuring Romina Oliveria, Kate Swaffer, and the late Richard Taylor who, together with their audience, examine the effects of language.

More recently DAI has focused again on **language and the media:**

In her blog, member **Whitney Mitchell** of the UK speaks eloquently about the experience of media and language in her world. She says, “*A diagnosis of dementia is bad enough – that’s the devastating news. But that’s where negative language can stop and positive language begin. If someone tells you day after day that you’re a ‘sufferer’ you end up believing it...It has a negative impact on a person’s well being.*”

Kate Swaffer, one of the founders of DAI, points out how more often than not the media in print, radio, and video share negative, stigmatizing, and demeaning stories that focus on only the deficits of a person living with dementia. In a blog earlier this year she states, “*The journalists I know personally, or have had online discussions with, all proclaim they are professional, and yet too many simply refuse to do the research about, and then actually bother to use, respectful dementia language. As our advocacy organizations are pushing globally for dementia friendly communities, and using the media to promote these campaigns, the time is NOW, that everyone needs to start using respectful language.*”