

Words Matter

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Heather is a consultant in person-centred care and DMT. She is currently very involved in issues around healthy, active ageing while continuing

to work as a DMT with families and children with disabilities.

The feminist movement of last century strongly highlighted the power of language not only to reflect societal/cultural perceptions and attitudes, but to form and reinforce them. The Australian Journal of Dementia Care (AJDC), in several recent issues, has invited discussion of appropriate language when talking about people living with dementia. While some may dismiss these concerns about language as an over-concern with political correctness, in fact the words we use have very real-life impact on the people we work with. How does it feel to be talked about as ‘victim’ or ‘sufferer’, a carrier of ‘behaviours’? What difference does it make in our professional behaviour when we view someone as being ‘demented’ rather than someone ‘living with dementia’?

As dmts, especially when we’re starting out, we may pick up the language used in the workplace. Sadly many terms around dementia still in common use, do not reflect modern views of what is respectful language when talking of the person living with dementia and tend to perpetuate negative (and often outdated biomedical) stereotypes. For that reason, it is good to see the issue raised in journals like the AJDC. Two excellent resources on what is currently considered more acceptable and positive language are also listed below: They are:

<https://fightdementia.org.au/sites/default/files/NATIONAL/documents/language-guidelines-full.pdf>

Dementia language guidelines from Alzheimer’s Australia, and

<http://daanow.org/living-fully-with-dementia-words-matter/>

Highlights the importance of language when talking about and to people with dementia. Available for free download: ‘See Me not my dementia’.

One term which still very much divides dementia professionals is the term ‘Behavioural and Psychological Symptoms of Dementia’, which one recent dementia workshop flyer defined as the words that “best encapsulate the *irrational* and *inappropriate* reactions of people with dementia”. This dispute essentially represents an ideological divide between a traditional biomedical view of dementia as brain pathology and behaviour as ‘symptom’, and a person-centred perspective, as exemplified in the work of Tom Kitwood, where behaviour is viewed not as a symptom of disease but rather the person’s response to an increasingly confusing life world. This division is not just a philosophical issue, but implies very different responses to the ‘behaviour’ of a person living with dementia – do we ‘manage’ symptoms of disease through medication and behaviour management, or do we seek understanding of what is happening for the person as a way to address their dis-ease (not disease!)?

These days people living with dementia are themselves talking up and demanding a more respectful, humanistic language (e.g. see Kate Swaffer’s blog post: <http://kateswaffer.com/2014/06/05/20-things-not-to-say-or-do-to-a-person-with-dementia/>).

As dmts working in the field of dementia, I believe it is important that we pay attention to such discussions and that we are prepared to look critically at the language we ourselves use about the people we work with. Words do matter!

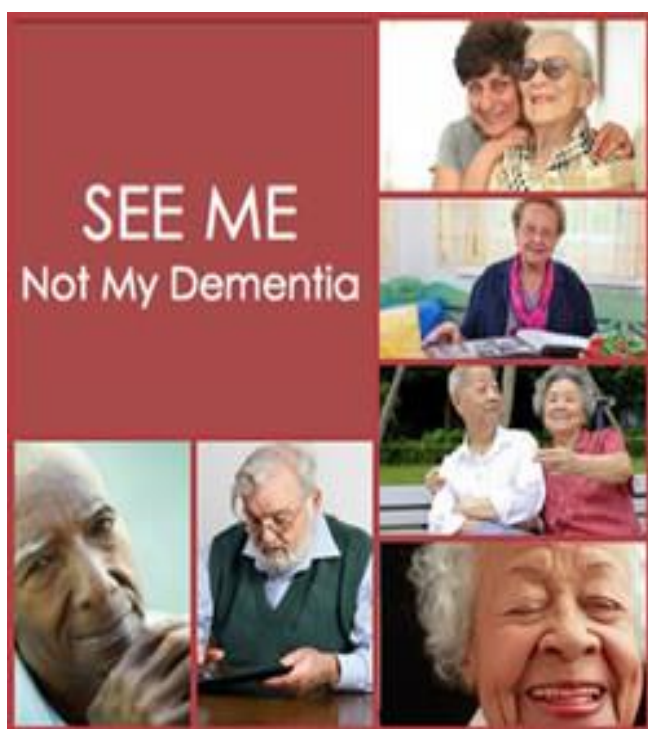
We are following this short article from Heather with some more writing on the subject of ‘Words Matter’ from the white paper produced by the DAA (Dementia Action Alliance). This was forwarded by Heather who says it draws quite a

bit on our Australian Alzheimer's Association framework of words that are acceptable and non-acceptable when talking about people with dementia. Heather stresses how very important it is for dmts working in the aged care field, and indeed in any area of healthcare, to be aware of and use appropriate, respectful language.

The following is drawn from the DAA's white paper.

Firstly, about the DAA, it is a "volunteer coalition engaged in changing understanding of and attitudes about dementia" and they (The DAA) are "committed to helping people live fully with dementia and supporting those who care about them." See:

<http://daanow.org/living-fully-with-dementia-words-matter/>



Under the heading of 'Living Fully With Dementia: Words Matter' the paper highlights how much the choice of words and terms do matter, particularly in relation to people who live with dementia - as the terminology adopted is so frequently derogatory and belittling. They provide examples of the words used such as 'demented', 'victim', and 'sufferer'. Also, that the condition can be described as a 'dementing illness' or an 'affliction', and that this can lead to negative perceptions and social isolation for the person involved. This of course makes living

with the dementia even more difficult than it needs to be because it creates more barriers to the person living life fully.

The language used about the person with dementia impacts on how they feel about themselves as well as how the person is perceived by others. Appropriate language should be respectful, supportive, and non-discriminatory. The term 'person living with dementia' acknowledges that dementia is not the defining aspect in the person's life, but rather is just one facet of his/her life. The paper provides really good examples of language that is recommended and language that should be avoided, with the rationale also provided.

For example, they suggest using 'Person living with dementia; or a specific condition' not patient as this is inappropriate when used outside of a medical event. And to avoid such words as 'sufferer', 'victim', 'demented' or 'demented person', 'senile', 'afflicted', 'not all there', 'behavior problem' etc. They advocate using Dementia as an inclusive umbrella term, rather than Alzheimer's, because this is only just one type.

They also address terms describing the 'carer' of the person with dementia. They recommend asking the person how they would like to be known, warning that 'caregiving' and 'care' can infer a one-way relationship. Words that recognize the reciprocity and caring relationship between the person living with dementia and their care partner should be used, for instance 'support' or 'support person'.

For more reading and downloadable pdf of the white paper go to

<http://daanow.org/living-fully-with-dementia-words-matter/>

and also follow up the other websites that Heather has provided.

Front cover of the white paper,

'SEE ME not my dementia'

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