Language and stigma

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Language is a powerful

Our words do reflect our thoughts and feelings, and can show respect or disrespect.

(Sabat 2001; Parker 2001; Hoffert 2006)
Language effects stigma, discrimination, isolation, quality of care, respect, quality of life and our ability to live better with dementia.
‘When your child is no longer a child, you will have to find a new language’

(Fossum, K 2003, don’t look back, p. 108)
... we are still mothers, fathers, lovers, daughters, wives or husbands, employees or employers, grandmothers, aunties;

it is a tragedy so many just see our deficits.
Language and dementia

- People with dementia continue to be labelled as ‘challenging behaviours’, by people without dementia, in ways that continue to marginalise and stigmatise us.
- This may seem simple semantics to someone without dementia, but it feels personal and important to me.
Stigma in the literature
Stigma in the workforce
Stigma in the media
Stigma in aged care
Stigma in acute care
Stigma in the community
20 things NOT to say or do to a person with dementia

1. Don’t say, ‘but don’t look or sound like you have dementia’
2. Don’t tell us we are wrong
3. Don’t argue with us or correct trivial things
4. Don’t say ‘remember when...’
5. Don’t call us ‘sufferers’ or ‘victims’
6. Don’t say we are ‘demented’, ‘demented sufferers’, ‘fading away’, ‘disappearing’, have a ‘dementing illness’, an ‘empty shell’, or ‘not all there’
7. Don’t say you are ‘living with dementia’ unless you are diagnosed with dementia
8. Don’t remind us of the death of a loved one or pet
9. Don’t blame the person for the changes in behaviour or personality
10. Don’t assume we do not understand you
11. We have a form or type of dementia, not an ‘affliction’
12. Don’t call me honey, love or anything other than my preferred name
13. Don’t refer to us as ‘aggressives, ‘wanderers’, ‘poor feeders’, ‘wetters’, ‘non-communicators’ or as ‘obstructive’ – we are still human beings
14. Don’t assume because we can’t tell you, your words or actions don’t hurt our feelings
15. Don’t assume I can’t answer for myself
16. Don’t talk about me to someone else, in front of me
17. Don’t assume we can’t communicate even if I can’t speak
18. Don’t say, ‘but I’ve just told you that’ or ‘you’ve asked me that already’
19. Don’t think we can’t feel pain, or emotions
20. Don’t assume anything, or that I don’t understand just because I am silent
Please embrace the Alzheimer’s Australia Language Guidelines 2014

SEE THE PERSON

NOT THE DEMENTIA


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Thank you