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The language of behaviour changes in dementia and why it matters

Emma Wolverson

<u>e.Wolverson@hull.ac.uk</u>

@EWolverson



Dementia is not only memory loss. To keep highlighting memory as the main disability keeps the myths alive. Kate Swaffer © 2021.



So many different terms!

Challenging Behaviour Unmet Needs Distressed Behaviour Non-Cognitive Symptoms Behavioural and Psychological Symptoms of Dementia Behaviour that Challenges Stress and Distress Unusual Behaviours Neuropsychiatric Symptoms Socially Unacceptable Behaviour BPSD NPS Dysregulatory Behaviour

(Word)ItOui

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Dementia Words Matter



- The language we use to talk about dementia influences how people with dementia are viewed and also how they feel about themselves.
- People with dementia prefer words and descriptions that are accurate, balanced and respectful.

#BanBPSD



Symptoms or Needs?

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Professionals

Wolverson, E., Birtles, H., Moniz-Cook, E., James, I., Brooker, D. and Duffy, F., 2019. Naming and framing the behavioural and psychological symptoms of dementia (BPSD) paradigm: professional stakeholder perspectives. *OBM Geriatrics*, *3*(4), pp.1-19.





Professionals

- Not blaming
- Easy to use
- Hopeful
- Reflection emotions



Wolverson, Moniz-Cook, Dunn & Dunning (in press).Family carer perspectives on the language of behaviour change in dementia: An online mixed methods survey. Age and Ageing.

Family carers



■ Heard of the term ■ Prefered ■ Least Prefered ■ Overall*



Family Carers

- Easy to understand
- Person Centered and positive
- Recognize role of the carer



People with dementia



Wolverson, E., Dunn, R., Moniz-Cook, E., Gove, D. and Diaz-Ponce, A., 2021. The language of behaviour changes in dementia: a mixed methods survey exploring the perspectives of people with dementia. *Journal of Advanced Nursing*, 77(4), pp.1992-2001.



People with dementia

- Simple easy to understand and kind
- Some terms were hopeless and implied nothing could be done
- Some blaming and implied intent
- No acronyms



Does it matter what language we use?

- Do we all need to use the same language?
- Can professionals use their own shorthand?





Reflections:

- We need to talk about changes in behaviour
- Take time to explore peoples language preferences and understandings
- Look to use words that reflect needs
- We need to continue to review the language we use in this area