

How Do Dementia Organisations Describe Behavioural Changes?

An Exploratory Cross-National Review of Terminology and Explanatory Approaches

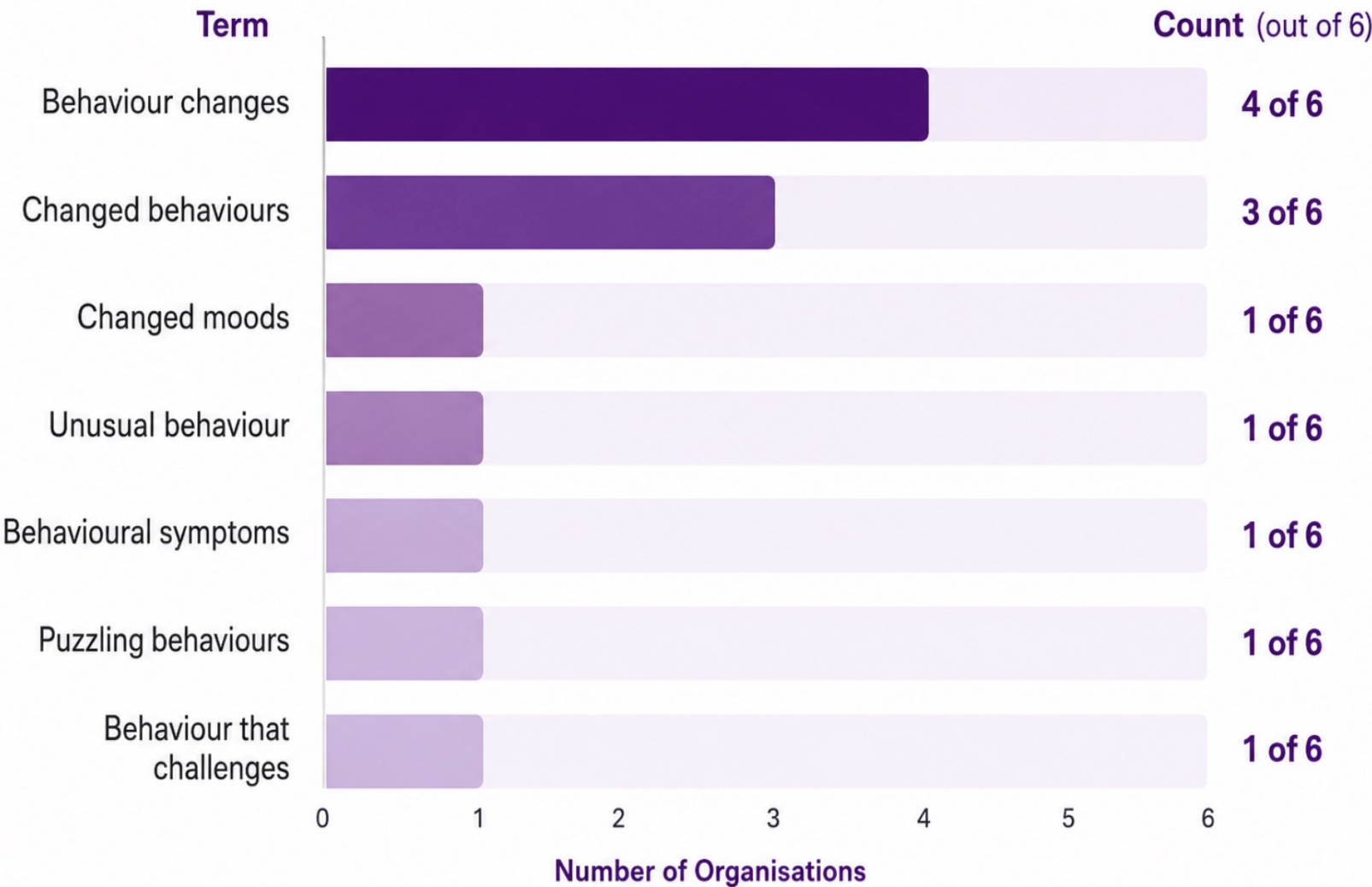


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KEY TAKEAWAY
Major dementia organisations described a largely consistent behavioural phenomenon using different terminology and explanatory approaches. The greatest variation lay in how behavioural changes were explained to consumers.
These findings provide a foundation for future research exploring whether consumer-facing terminology and explanatory framing may influence caregiver understanding.

INTRODUCTION	METHODS	RESULTS	CONCLUSIONS	REFERENCES																
Behavioural changes are common in dementia and are among the leading reasons caregivers seek information and support. Dementia organisations provide consumer resources, yet little is known about how behavioural changes are described and explained across organisations. Common clinical terms include: BPSD NPS Behaviour changes / changed behaviours Consumer resources help shape caregiver understanding but may use different terminology and explanatory frameworks than clinical literature. <i>To our knowledge, limited work has examined how major dementia organisations describe behavioural changes in publicly available resources.</i> The Real Question <i>Not just “what words do they use?” but “how do dementia organisations conceptualise behavioural changes when communicating with the public?”</i> Strengths - Cross-national comparison of major English-speaking dementia organisations. - Focus on publicly available consumer resources, directly relevant to caregivers. - Transparent, exploratory methodology appropriate to the research question.	Organisation Selection - Major national dementia organisations from selected English-speaking countries, together with one international federation, were purposively selected. - The first relevant publicly available, consumer-facing webpage addressing behavioural changes was identified for each organisation.  Dementia Australia Australia  Alzheimer's Association United States  Alzheimer's Society United Kingdom  Alzheimer Society of Canada Canada  Alzheimers New Zealand New Zealand  Alzheimer's Disease International Global Search Strategy 1. Website search 2. Behaviour page identified 3. Terminology extracted 4. Explanatory framing categorised <i>Searches conducted: April 2026</i>	Terminology Used Across Organisations (n = 6) <table><thead><tr><th>Term</th><th>Count (out of 6)</th></tr></thead><tbody><tr><td>Behaviour changes</td><td>4 of 6</td></tr><tr><td>Changed behaviours</td><td>3 of 6</td></tr><tr><td>Changed moods</td><td>1 of 6</td></tr><tr><td>Unusual behaviour</td><td>1 of 6</td></tr><tr><td>Behavioural symptoms</td><td>1 of 6</td></tr><tr><td>Puzzling behaviours</td><td>1 of 6</td></tr><tr><td>Behaviour that challenges</td><td>1 of 6</td></tr></tbody></table> Use of Clinical Terminology: 1 of 6 organisations used BPSD 0 of 6 organisations used NPS All six organisations described the same phenomenon. Terminology differed, but the underlying behavioural phenomenon was largely consistent. How Organisations Explain Behavioural Changes Organisations explained behavioural changes using three recognised conceptual approaches (Cohen-Mansfield, 2000; Kitwood, 1997). Symptom-based Behaviour is explained primarily as a consequence of neurodegenerative disease. Needs-based Behaviour is explained as signalling an unmet physical or psychosocial need. Person-centred Behaviour is explained as meaningful communication shaped by individual experience.	Term	Count (out of 6)	Behaviour changes	4 of 6	Changed behaviours	3 of 6	Changed moods	1 of 6	Unusual behaviour	1 of 6	Behavioural symptoms	1 of 6	Puzzling behaviours	1 of 6	Behaviour that challenges	1 of 6	Key Findings: - Consumer-facing terminology differed across organisations. - Clinical terminology (BPSD/NPS) was rarely used. - Organisations described a largely consistent behavioural phenomenon through different explanatory approaches. - Most organisations combined symptom-based, needs-based and person-centred explanations. Limitations - Only one webpage from each organisation was reviewed. Future Directions - Expand to non-English speaking countries and organisations - Qualitative studies exploring caregiver interpretation of terminology - Explore whether caregivers interpret behavioural changes differently across explanatory frameworks What This Contributes <i>This exploratory review identifies variation in consumer-facing communication about behavioural changes and provides a foundation for future work examining whether terminology and explanatory approaches influence caregiver understanding.</i>	References - Cohen-Mansfield J. Theoretical frameworks for behavioral problems in dementia. Alzheimer's Care Today. 2000;1(4):8–21. - Kitwood T. Dementia Reconsidered: The Person Comes First. Buckingham: Open University Press; 1997. - Dementia Australia. Mood and behaviour changes [Internet]. Sydney; [cited 2026 Apr]. dementia.org.au - Alzheimer Society of Canada. Dementia and behaviour [Internet]. Toronto; [cited 2026 Apr]. alzheimer.ca - Alzheimer's Association. Treatments for behavior [Internet]. Chicago (IL); [cited 2026 Apr]. alz.org - Alzheimer's Society. How does dementia change a person's behaviour? [Internet]. London; [cited 2026 Apr]. alzheimers.org.uk - Alzheimers New Zealand. What happens in the later stages of dementia [Internet]. Wellington; [cited 2026 Apr]. alzheimers.org.nz - Alzheimer's Disease International. Symptoms of dementia [Internet]. London; [cited 2026 Apr]. alzint.org CONTACT Yumna Elsedfy Frazer Institute The University of Queensland y.elsedfy@uq.edu.au
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