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PrAISED

Promoting Activity, Independence  
and Stability in Early Dementia

# The Experiences and Understanding of Apathy in People with Dementia and MCI: A Qualitative Interview study

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- Reduced interests, initiative, emotion, effort & motivation
- Common in dementia and MCI
- Associated with negative outcomes
- Not well understood and disagreements remain about what apathy is
- Little research into the experiences and understanding of apathy in people with dementia and MCI or their carers





- PrAISED participants from 4 sites
- September - December 2019
- 16 semi-structured dyadic / individual interviews
- Reflexive thematic analysis



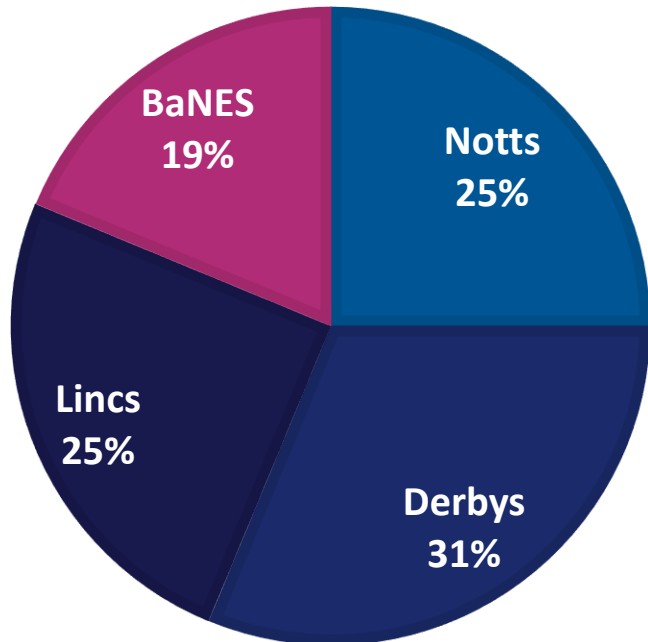
# Participant characteristics

- Mean Participant Age = 75.6yrs (range: 66-91)
- Mean Carer\* Age = 72.3yrs (range: 50 – 89)

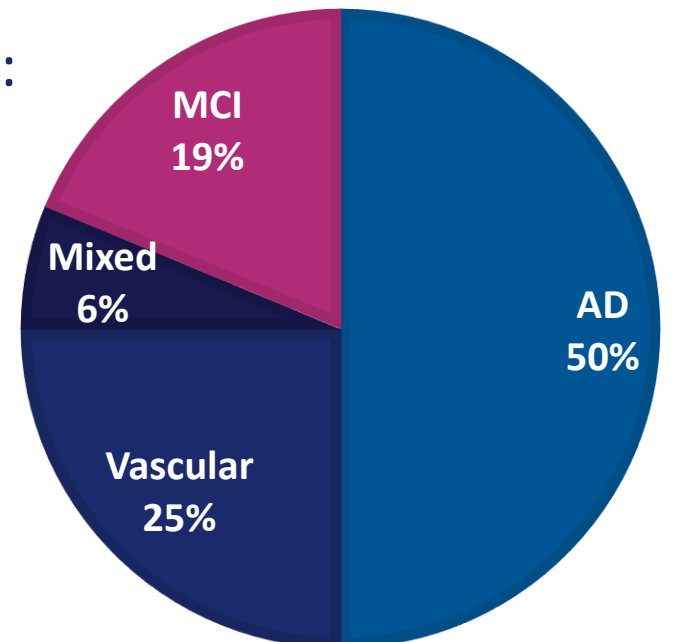
\*carers who participated in the interviews

- 31% Female
- 94% White
- 44% College / University
- 81% had a spousal carer

Area recruited from:



Diagnosis:





Apathy is Poorly Understood

'Too much trouble': Mediating Effort and Outcome

Preserving Identity in the Face of Loss of Capability and Autonomy

Opportunity and Exclusion



“

*I just don't care anymore. I can sit here all day looking out of that window without even thinking about it.*

- Chris, 91-year-old with AD

“

*Nick: Never heard it before. Apathy? What do you mean, feeling sorry for yourself? Is that what you mean? Oh I don't know what it means.*

*Cynthia: No, I don't.*

*Nick: Apathy... no.*

*Cynthia: I have to say it's not one of our words, let's put it that way.*

”

-Nick, 85 year old with VaD, and Cynthia, 76-year old carer

”



## Daily Struggle



*He can't walk like he used to. And he can't think like he used to. [...] now everything is an effort.*



- Martha, 73-year-old carer

## Impact of Consequence & Purpose



*Sandra: Robert mixing with new people is not great.*

*Robert: ... yes. Because it seems like I'm frightened, because I don't know what I'm going to say and it's hard to get conversation. You know what I mean?*



- Robert, 66-year-old with AD, and Sandra, 61-year-old carer

### Threatened Identity

“ I don't really like that, after being top dog and sort of organising everything, I might find it a bit difficult not to. I would want to interfere, and I can't do that. I would want to take control [...] even if I haven't got the capacity or capability to do it, I'd still feel I would want to if I was there. ”

- Jean, 85-year-old with AD

### Preserving the Competent & Autonomous Self

“ Well, it's one of those things. If you can't do it you can't, can you? And um, I don't rail against things that I can't do, I just get on and do the things I can do, which isn't very much. ”

- Anne, 87-year-old with AD





“

*I don't worry about it, just... sit here. That's all you can do. She says I don't do nothing, I'm sat here all day. But what else can I do?*

”

- Nick, 85-year old with VaD

“

*I said I'm finding it difficult to follow you, can you give me notes? He said no, I won't give you notes. That's what he said. [...] and he gave notes at the end but then, the notes didn't make any sense to me.*

”



- Rahul, 76-year-old with MD



- Alternate terms may be preferred.
- Apathy should not be considered in isolation from cognitive and physical impairment, or the wider context.
- Apathy is experienced as an understandable response to changes in ability.
- It is exacerbated by lack of support and opportunities.
- Increasing support, inclusion, need and sense of purpose could reduce apathy.



Thank-you for listening.

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