



From symptoms to stories of people: a person-centred understanding of behaviours that challenge others in advanced dementia

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Person-centred approaches to understanding and care

- **Origins go back over 25 years**
 - “.. ‘know the person’ ...” (1990)
 - ‘Person first, dementia second’ (1995)
- **Tom Kitwood (1997) – “the person comes first”**
 - “should no longer be person – with – DEMENTIA, but PERSON – with – dementia.”
- **Yet 30 years on it is too often either -**
 - a misunderstood concept – reduced to the status of an intervention invariably predicated on a shallow understanding of what it means to be a person, *or*
 - a misused concept – degraded to a marketing strap line.

Person-centred understanding

- Valuing the uniqueness of the person with dementia. We learn about the person's life, their family, their values and beliefs, and how they like things to be done. Their day, in their way
- Appreciating that we share more in common with a person living with dementia than what separates us. This means acknowledging their need to be pain free and a need for affection, self-respect, occupation, human contact, peace of mind, a sense of belonging and 'to matter'.
- Being there as they live their life in a world of not knowing, mystery and insecurity - a world that we can barely comprehend.

Behaviours that challenge others are symptoms of dementia

Behavioural and Psychological Symptoms of Dementia (BPSD)

“It’s because they have dementia”



Wandering

Diagnostic overshadowing

To believe otherwise results in cultures of care that resonate with the need to control and contain; cultures that only aspire to cope and manage

The questions that enabled the paradigm-shift from pathology to person

1. Why are only some people with dementia challenging to others? Inter-individual differences

That which people with dementia share in common you can attribute to the disease, that which they do not share in common you can rarely attribute to the disease

2. Why are behaviours experienced as challenging often specific to a certain context or sometimes to time? Intra-individual differences

What it means to be Mrs S – her life, her story



You are who you are, and it is who you will remain

- Women who squat to avoid making contact with the toilet seat - **72.6% sometimes or always**
- Women who place toilet paper on the seat before sitting on it - **60.8%**
- Women who wipe round the toilet seat prior to using it - **83.6%**
- Women who avoid touching the flush handle by using, e.g. paper or another part of their anatomy - **56.1%**
- When washing their hands, women who avoid touching the taps by using their wrists to turn taps on and off - **44.0%**
- Women who on leaving the toilet avoid touching the door handle – **47.3%**

Jane: A toilet 'crawling with worms'

Challenge: Toilet refusal with accompanying aggressive resistance

Incontinence pads rejected

Neuropsychological assessment = perceptual disturbance (i.e. agnosia)

Toilet floors - black and white floor tiles

Person variable **Fear of worms**

(Moniz-Cook, Stokes and Agar, 2003)



Revised Care Plan: Function, Formulation and Intervention

Function: Behaviour is a flight-fight response when confronted with an anxiety provoking stimulus

Formulation: Agnosia is resulting in misperception of black and white tiles. Seen as black lines on a white background. Lines misinterpreted by Jane as worms. The outcome is dread, anxiety and if care action persists, panic and resistance

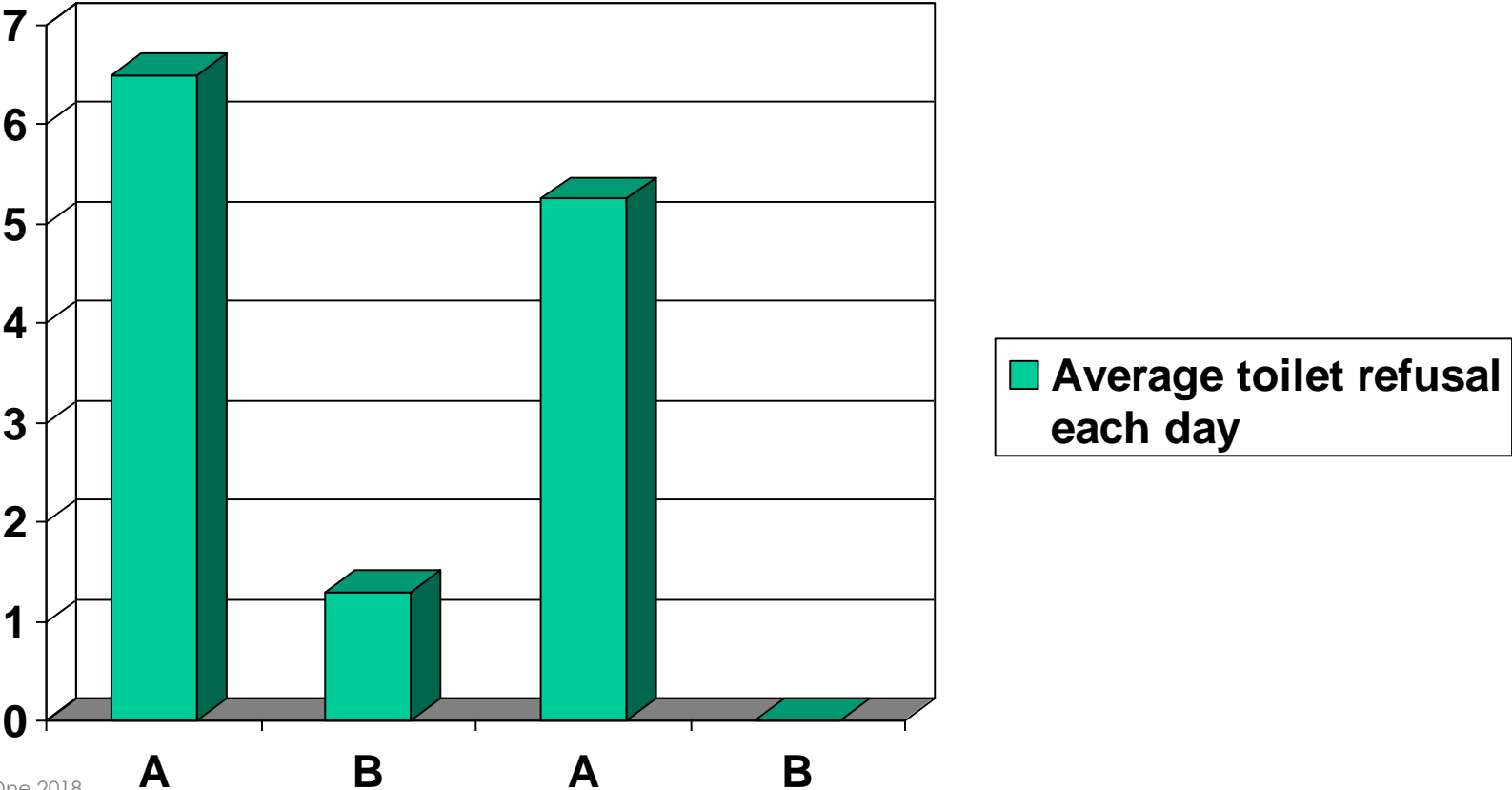
Primary causation: Fear of worms

Secondary causation: Role of dementia - impairment of memory, communication and reasoning, and agnosia

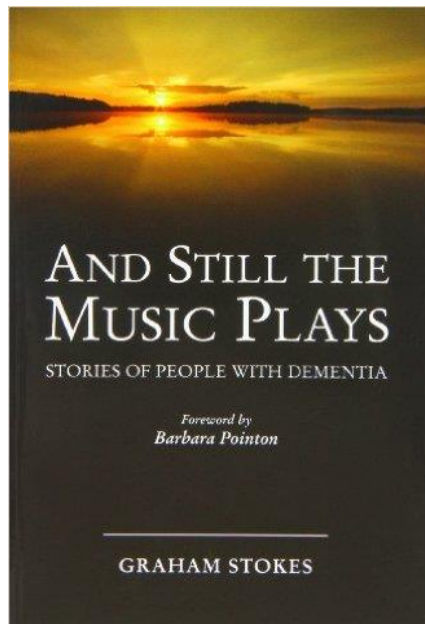
Action: **Paint toilet floor dark red**

Outcome: Appropriate independent toilet use

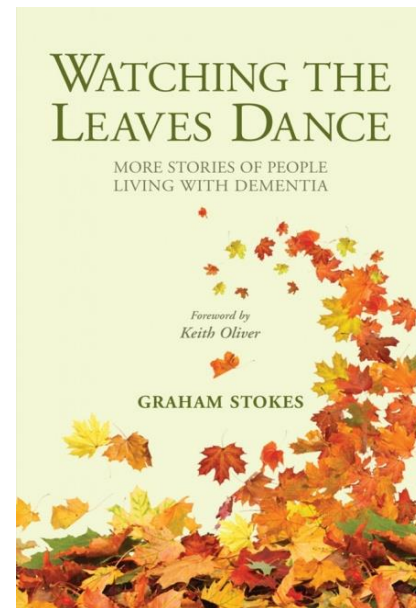
Research Results



Walter – It is not death he feared



“I dread the prospect of this wretched illness. Destroying my brain, dementia is taking away who I am and all I know. My girls, people, places, my contribution to the lives of others. What is life if not remembered? Death I do not dread. If truth be told this is the answer, my solution, for I fear disability and degradation more than death itself.”



Thank You

