Caring for People with Dementia: Reality, myth or a journey of reflection and discovery

Dr Graham Stokes

Divisional Director of Dementia Care, Bupa Care Services

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Contemporary Understanding of Dementia

Pathology-centred (biomedical) model of dementia – traditional. Dating back to Arnold Pick in 1892, Otto Binswanger in 1894 and Alois Alzheimer in 1906.

Personhood

- The greatest transformational change in dementia care is embraced by the word – **person.**

- People living with dementia.

- I wrote in 1990 it's "***person first, dementia second***".

That which people with dementia share in common you can attribute to the presumptive disease (most commonly Alzheimer's disease), that which they do not share in common you can rarely attribute to the disease

We remain who we are

- Women who hover 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%**
- Women who on leaving the toilet avoid touching the door handle – **47.3%**

“Senile dements”

- For most of the twentieth century dementia did not possess a human face. We worked with shells, shadows and bodies.

- Any sense of there being a person with dementia flickered, faded and was ultimately extinguished as pathology and despair dominated all.

Person-centred model of dementia – a reconsideration. Over past 20 years has delivered a paradigm shift.

- possibly

The Emperor's New Clothes

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Supporting evidence

- Diagnostic overshadowing persists – 'it's because they have dementia'
- Therapeutic nihilism
- Excess use of antipsychotic medication to control Behavioural and Psychological **Symptoms** of Dementia (BPSD) – In the UK October 2009 target to reduce prescribing/use by 65% by March 2012
- **In part excess prescribing persists because understanding of what constitutes person-centred methodology is too shallow**

The pathology-centred model is not to be rejected

- Pathology-centred model is diagnostic
- Dementia is conceptualised as an intellectual disability

Person First, dementia second – how does a person with dementia survive; how do they communicate their needs; how do they tell us their fears?

The Person-Centred Understanding Coalesces Around the Individual and their Setting

- A person who is unique
- Yet with whom we share more in common than what separates us
- Enduring a world of not knowing, resonating with threat, mystery and insecurity - a world that we can barely comprehend -

And the experience is embraced by an absence of insight. A person who does not know they have dementia, whose awareness of their dependency and vulnerability is at most fleeting and who as a result does not know they need us

The essence of dementia care

Dementia care is caring for people who do not know they need to be cared for

A person who is unique

- Joan's story
- Jane's story

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.

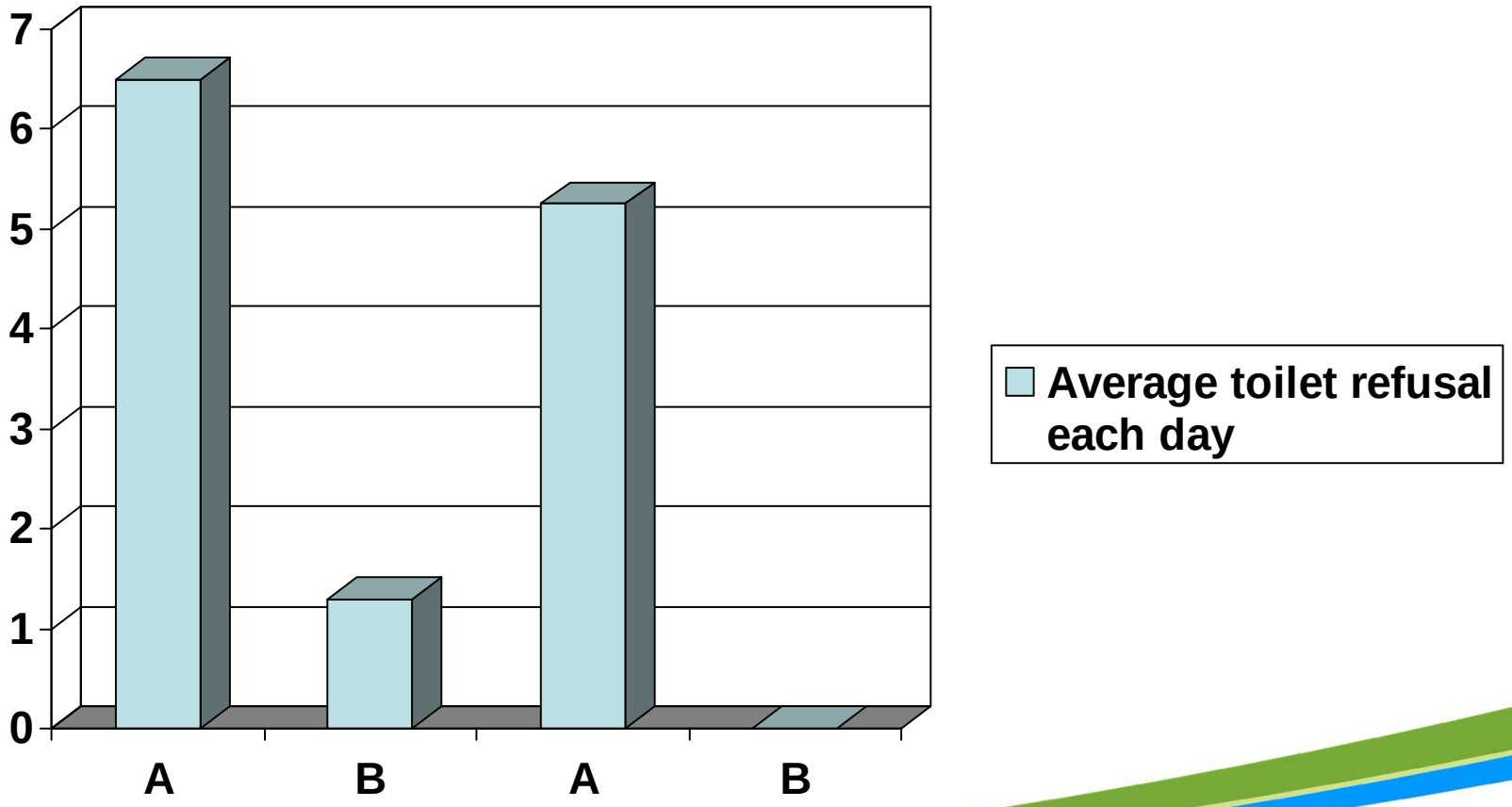
- **Primary causation: Fear of worms**

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

- **Action: Paint toilet floor dark red**

- Proposed outcome: Appropriate independent toilet use

ABAB results



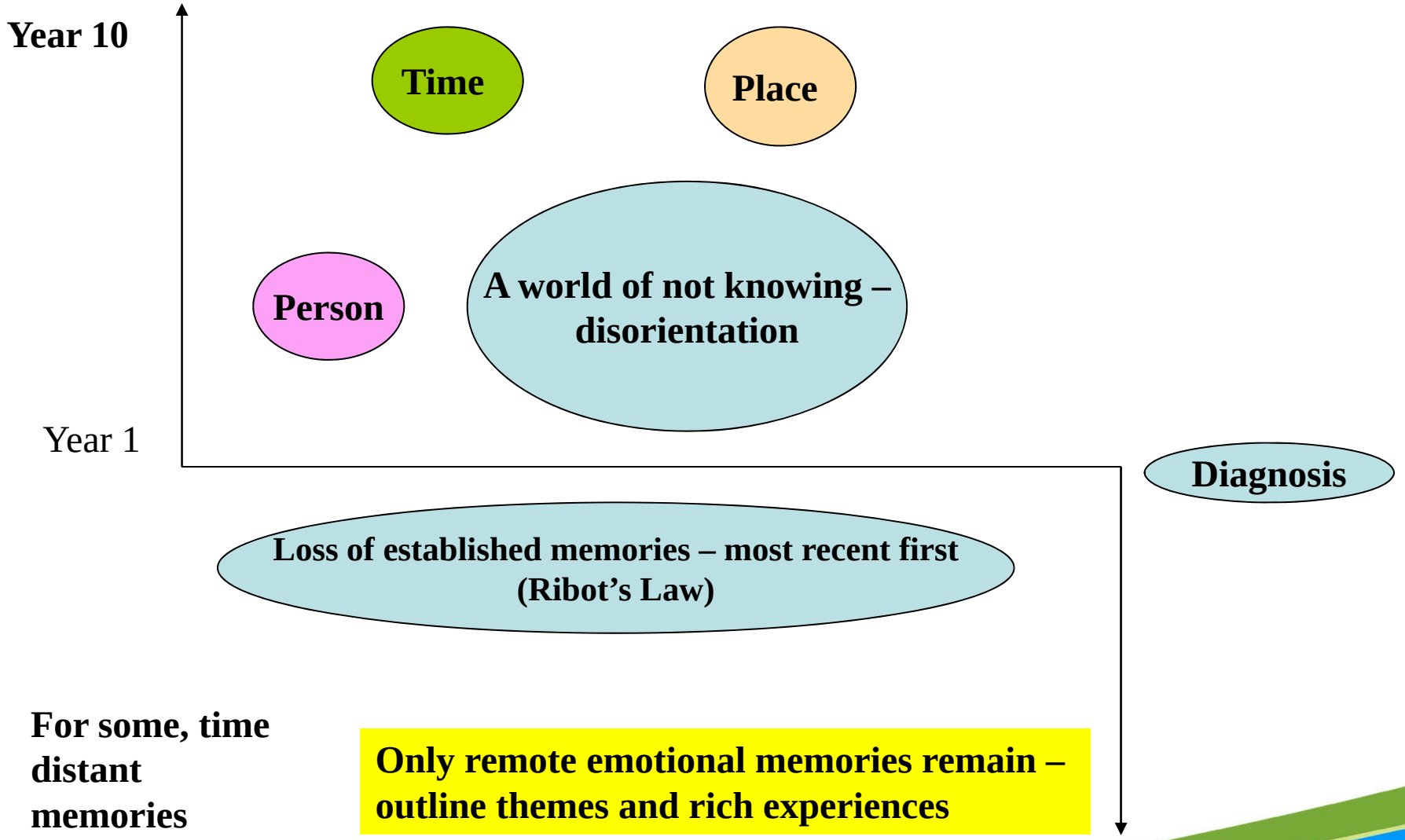
“That’s not our aunt.”

A shared humanity

- Shared fundamental human needs
- To be free of pain, psychological security, human contact, occupation, respect, belonging and affection.
- Innate or the product of early learning
- Patrick's story

The experience to understand

- Not just about knowledge and skills, but also hearts and minds – the need for empathy
- For most people living with dementia is an advancing world of not knowing
- But for some it is a world of knowing



For some, time distant memories become a restored reality

Only remote emotional memories remain – outline themes and rich experiences

Sylvia's story

A life that is fragmented and experienced without an underpinning narrative to provide cohesion and reassurance

Person First – bite size

- **Know the person living with dementia as a unique individual**
- **Respect the person with whom we share a common humanity**
- **Walk in their shoes**

The obstacles facing the paradigm shift (i)

- The authority of the pathology-centred model - 'doctor knows best'
- The words of families - 'that is not.....' – so who is it?
- The behaviour places the person outside of the human constituency
- The barrier to communication set up by the intellectual disability
- Social distancing as a defence
- The simplicity of the pathology-centred model is seductive

The obstacles facing the paradigm shift (ii)

- There are no prescribed solutions
- A concern for what we so often do – the challenge of competing, conflicting needs
- Family carers reach a point on the journey when to self-protect they need to seek comfort in the knowledge that the person has departed
- Professional carers are emotionally unsupported at a time when their work is making them psychologically aware
- The pathology-centred model absolves us of all responsibility