



The Need To Transform Services In Care Homes

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Using the UK as an example: Care homes and dementia care

- 432,000 people in care homes in the UK.
- In England Alzheimer's Society (2013) now estimate **80% of people in care homes have dementia or significant memory problems.**
- More than 300,000 people with dementia live in care homes most with high dependency, challenging and end-of-life care needs
- 40% of all people with dementia in the UK



But what do we mean when we talk about dementia care?



It is caring for people whose brains are so damaged by disease their **dementia renders them incapable of taking responsibility for their hygiene, personal care and daily lives.** It is **caring for people whose judgement is so diminished** they cannot take responsibility for their actions and who as a result engage in unacceptable risks

...Except it is not...

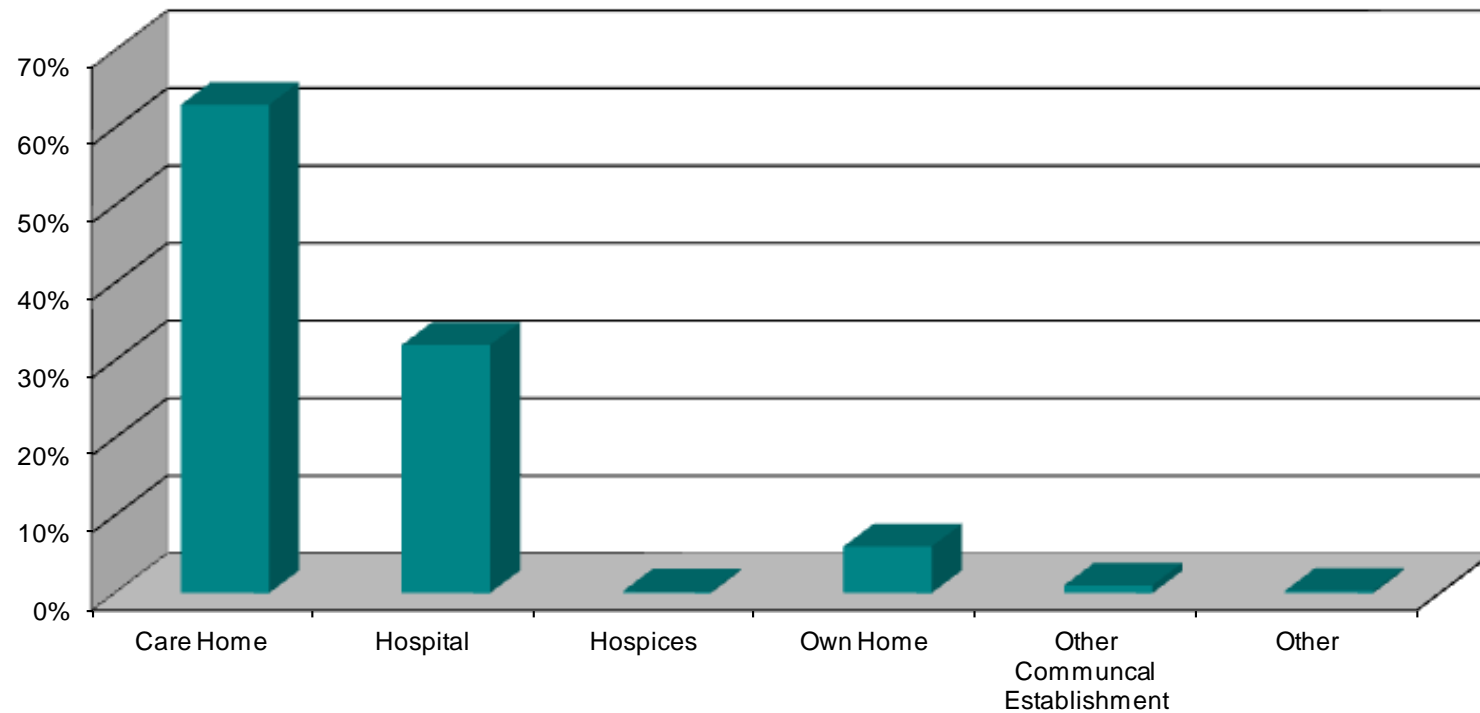
It's caring for people who do not know they need to be cared for.

**When people with dementia know they need us, they need us least;
when they need us most, they know they do not need us at all.**

So we need to rethink how we care for people living with dementia

Where people with dementia die in the UK

Deaths where dementia was the underlying cause (2012)



People's expectations of care are low

Alzheimer's Society | Leading the fight against dementia

Low expectations

Attitudes on choice, care and community for people with dementia in care homes



Low Expectations (Alzheimer's Society 2013)

http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1024

- 68% of residents' relatives said quality of care was good.
- Less than half of relatives (41%) said the person with dementia had a good quality of life

The Key Message

There is a distinction between quality of care and quality of life

It is not one and the same thing

Good care contributes to a person's quality of life and to think otherwise sets the bar far too low

The need to identify and prioritise unanswered questions

Dementia Priority Setting Partnership with the James Lind Alliance: Using patient and public involvement and the evidence base to inform the research agenda.

Sarah Kelly, Louise Lafortune et al. (on behalf of the Dementia Priority Setting Partnership steering group)

http://alzheimers.org.uk/site/scripts/download_info.php?downloadID=1427

- The JLA Dementia Priority Setting Partnership was an evidence-based project to identify and prioritise unanswered questions ('uncertainties') about the prevention, diagnosis, treatment, and care relating to dementia.
- The PSP process was conducted between April 2012 and June 2013
- Uncertainties were collected via a survey disseminated to a wide range of stakeholders.
- Thematic analysis was developed to manage and generate research questions.
- Each question was checked against an extensive evidence base of high quality systematic reviews to verify they were true uncertainties
- The top ten list of dementia research priorities provide a focus for researchers, funders and commissioners

Dementia Priority Setting Partnership top 10 priorities - the five with direct relevance to care homes

We know that we need to transform care homes, these questions will help us think how to design new services:

What are the most effective components of care that keep a person with dementia as independent as they can be at all stages of the disease **in all care settings?**

What non-pharmacological and/or pharmacological (drug) interventions **are most effective for managing challenging behaviour** in people with dementia?"

"What is the **best way to care for people with advanced dementia** (with or without other illnesses) at the end of life?"

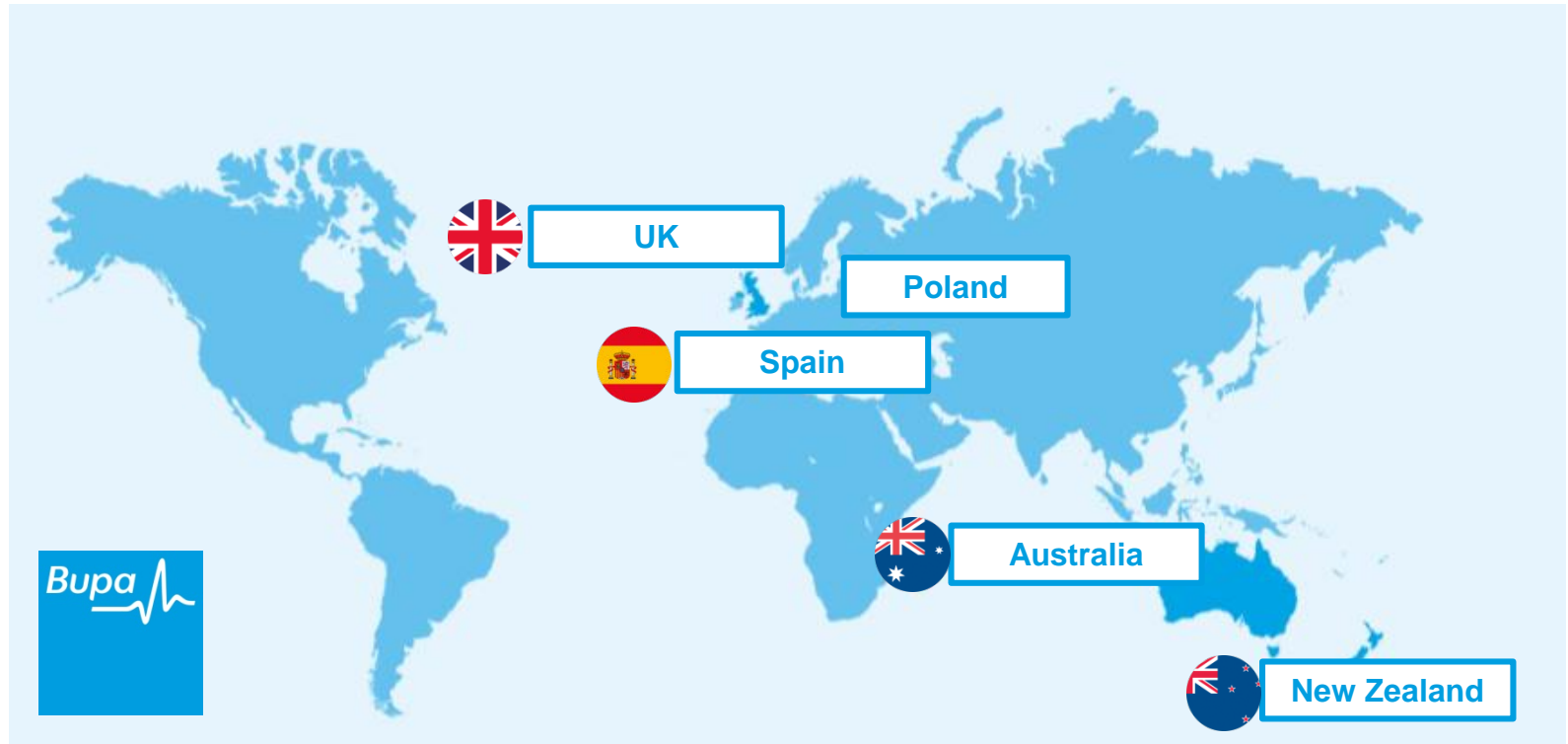
What are the **most effective design features** for producing dementia friendly environments at both the housing and neighbourhood levels?

When is the optimal time to move a person with dementia into a care home setting and **how can the standard of care be improved?**

Sarah Kelly, Louise Lafortune et al. (on behalf of the Dementia Priority Setting Partnership steering group)

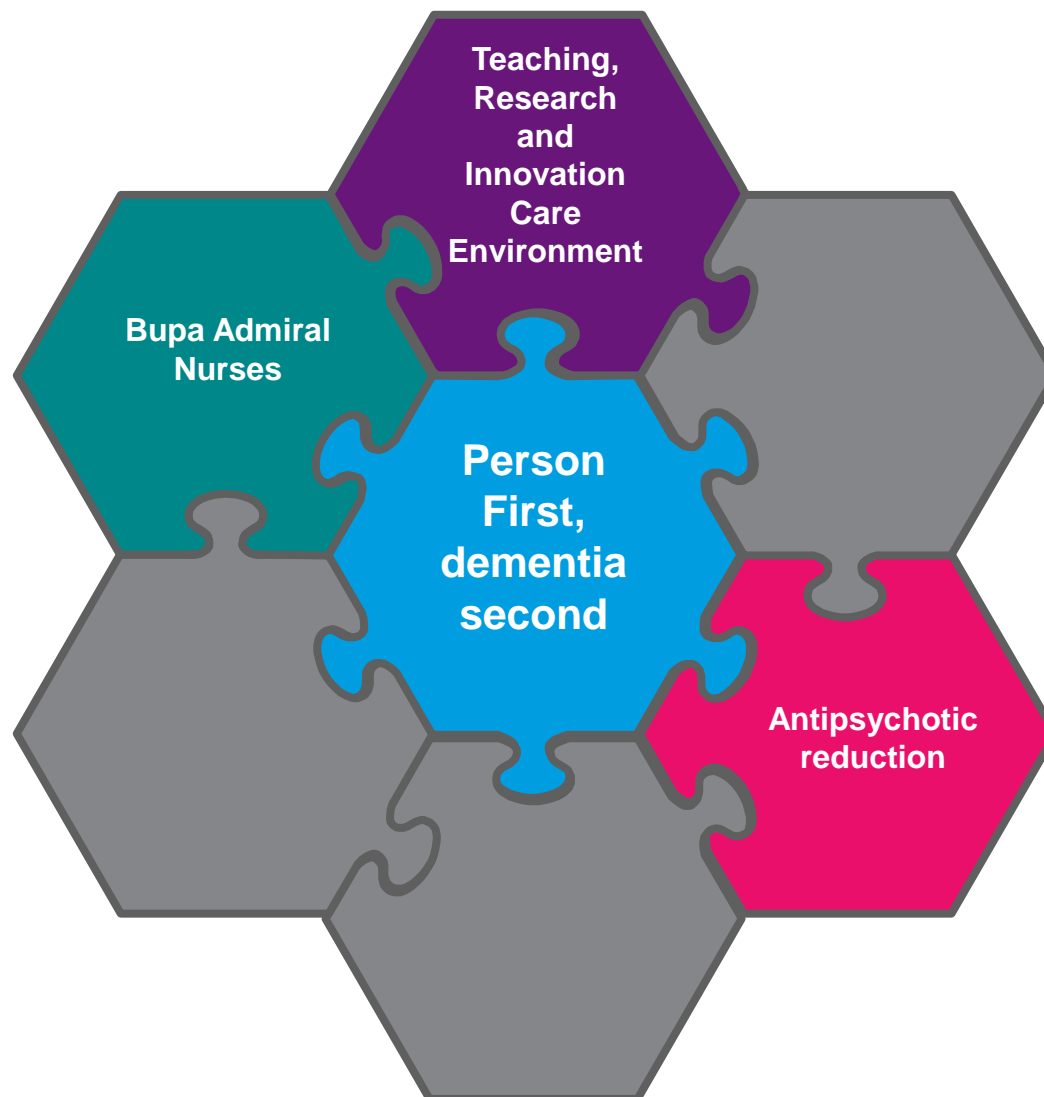
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Four national care home businesses providing dementia care



- **Bupa cares for approximately 24,000 residents** with dementia across the world, most with advanced Alzheimer's disease, complex behaviours and/or multiple morbidities
- **We are the only global provider of dementia care** (and in 2015 services will expand into Poland)
- **In the UK** 171 care homes provide specialist dementia care, caring for 7,000 residents
- Another 7,000 people with dementia are living on frail elderly units because they have multiple co-morbidities and/or end of life care needs

Bupa - raising standards of dementia care in the UK



Antipsychotic reduction programme, 2009 - 2014

- 2009 - **35.0%** residents with dementia prescribed antipsychotics
- 2013 - **19.5%** residents with dementia prescribed antipsychotics



Antipsychotic reduction programme: New ways of working

- **Person First, dementia second staff training programme. Launched 2010**
- **Behavioural analysis** (Stokes G, 2000. Challenging Behaviour in Dementia: A Person-centred Approach, Winslow Press)
- **Functional analysis** (Moniz-Cook E, Stokes G and Agar S. Difficult behaviour and dementia in nursing homes. Clinical Psychology and Psychotherapy, 2003, 10: 197-208)

Appreciative Enquiry

Admiral Nursing in the UK

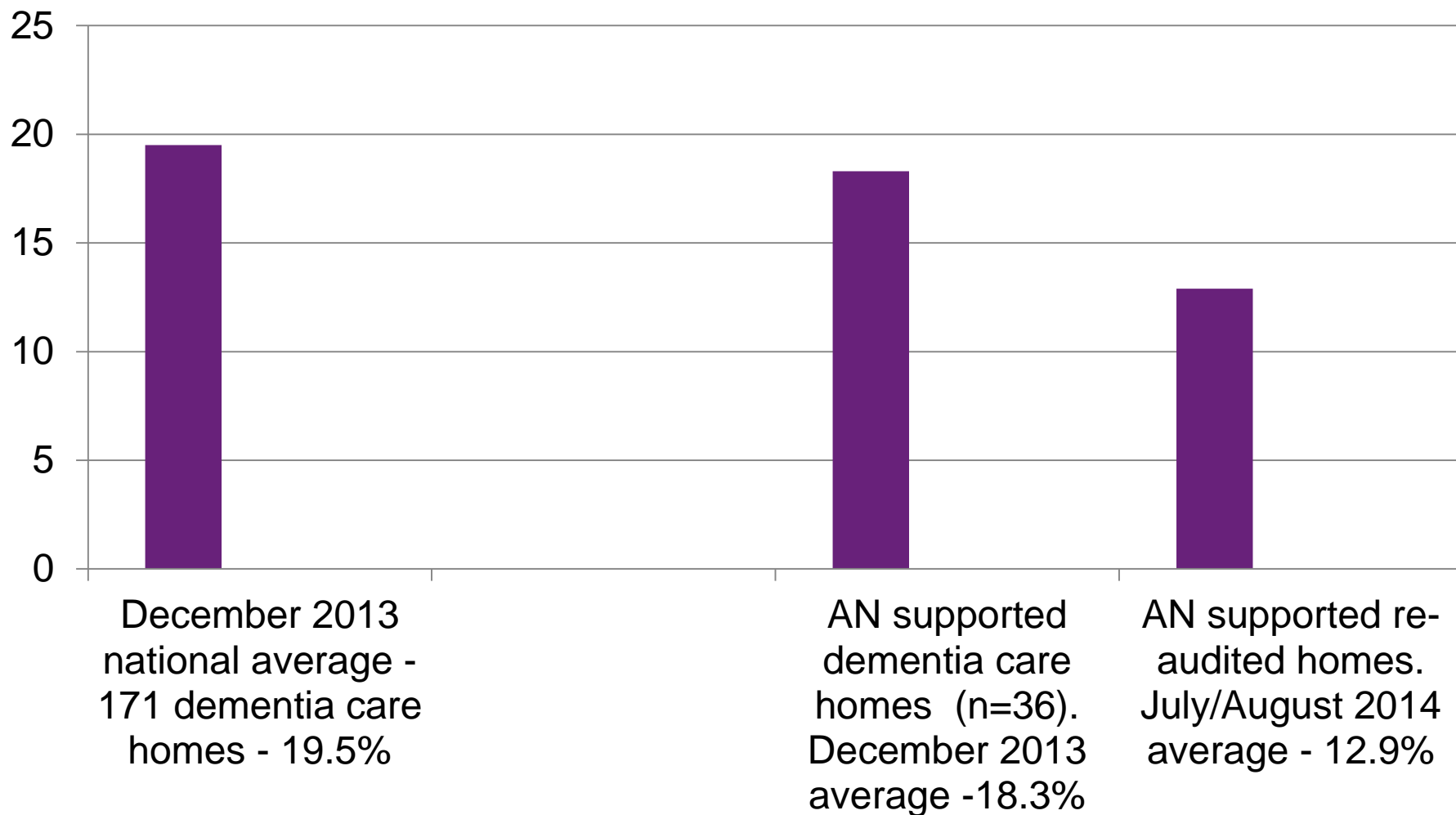
What is an admiral nurse: Dementia Care Specialist Nurses



Bupa Admiral Nurses

- Appointed in 2013
- 6 currently in post across in England
- **6 more to be appointed in 2015 in England and Scotland**
- An external layer of extraordinary capability currently supporting 40 dementia care homes

Admiral Nurses are delivering great results in reduction of prescribed antipsychotics



A Proposed Teaching, Research and Innovation Care Environment



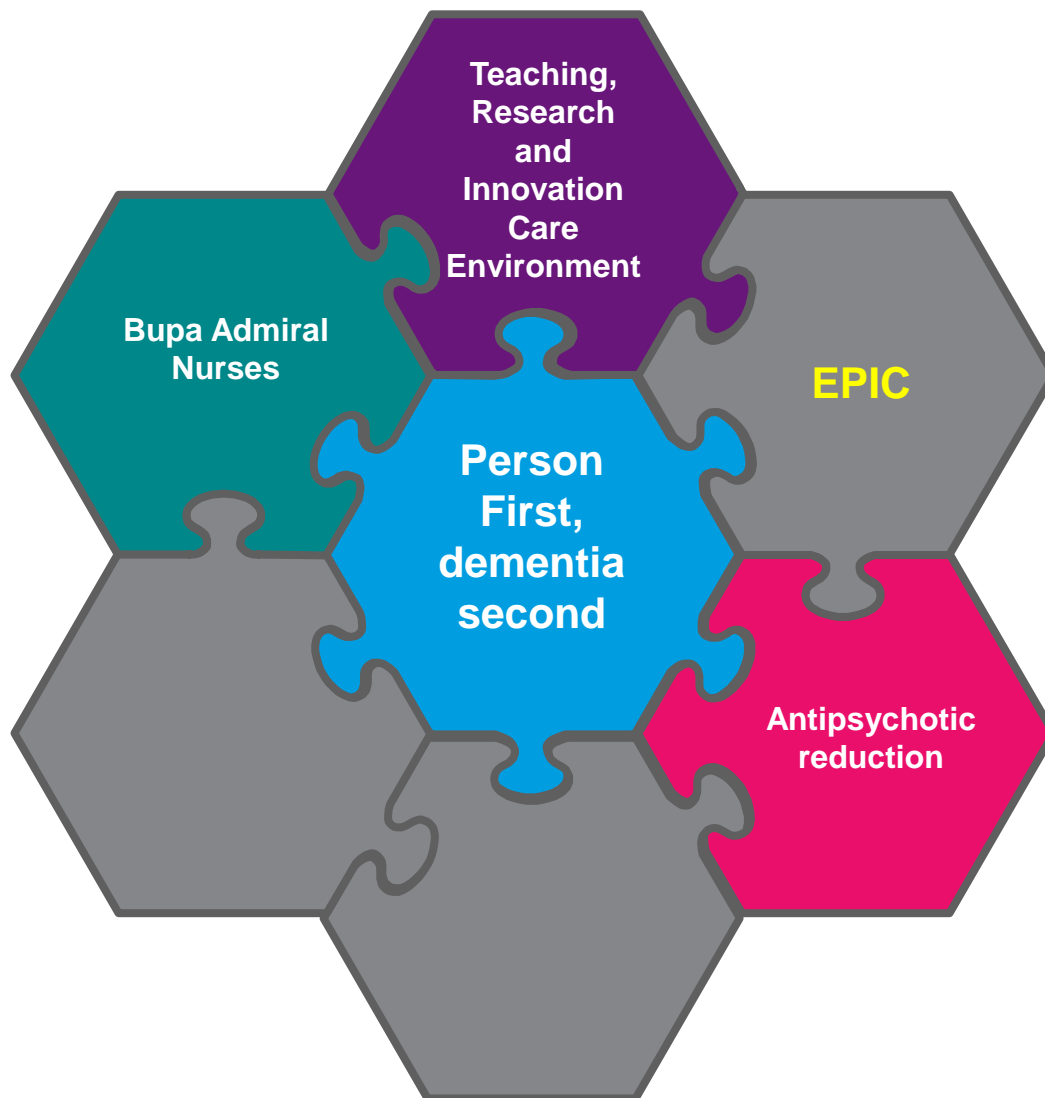
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The environment will be a research-rich, scholarly environment testing design principles, clinical practice and care innovation. Hosted in the United Kingdom, led and delivered by outstanding dementia care practitioners, academics and researchers from the Bradford Dementia Group, it will be a global exemplar, using research-informed training and practice development.

There are still pieces of the puzzle missing...



Evaluating the effectiveness and cost effectiveness of Dementia Care Mapping (DCM) to Enable Person Centred Care Training (PCCT) for people with dementia and staff: A UK cluster randomised controlled trial In Care homes (DCM EPIC trial). Lead applicant, Dr Claire Surr (University of Bradford Dementia Group).