

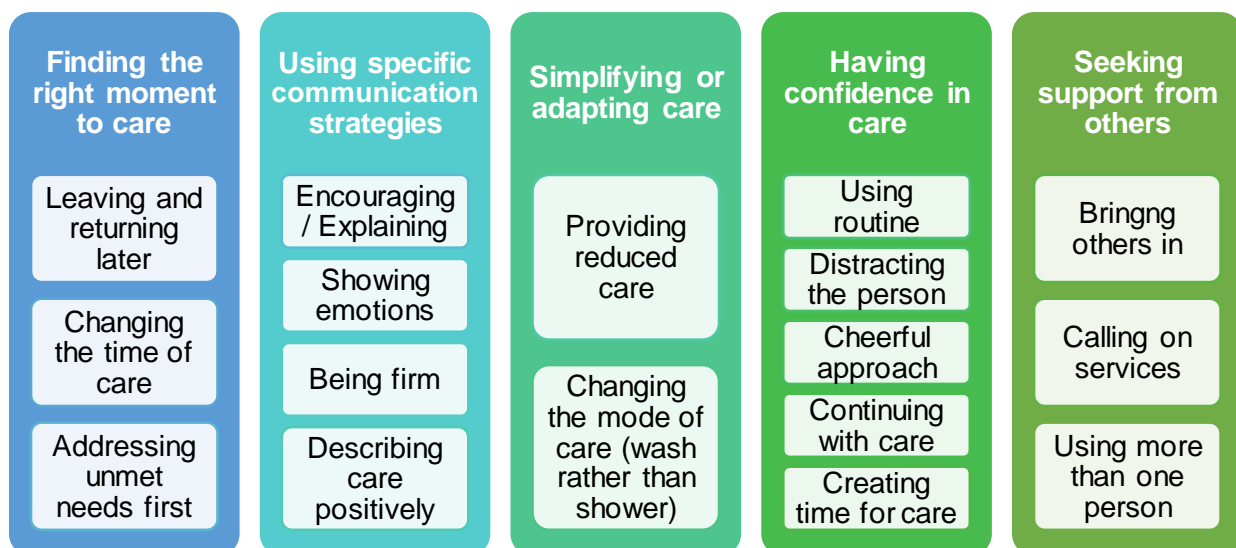
## Findings from the Pro-CARE Study:

**Learning about refusals of personal care when assisting people with advanced dementia.** This research was conducted by Dr Tamara Backhouse and colleagues at the University of East Anglia and funded by a fellowship from the Alzheimer's Society. The research team for the Pro-CARE study was supported by family carer and care-home staff advisors throughout.

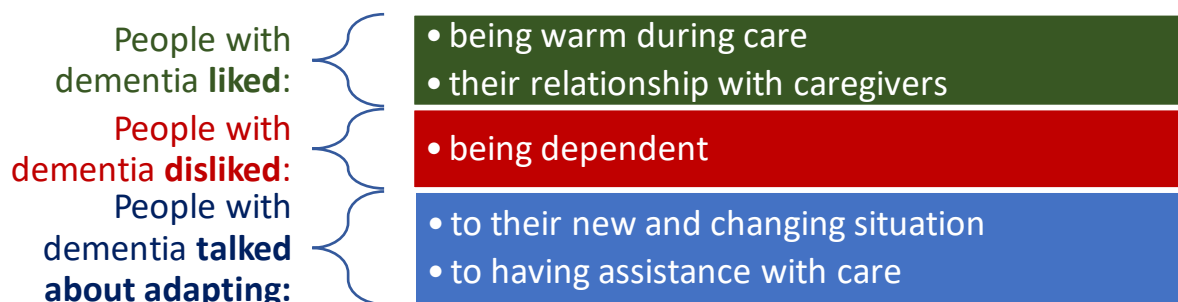
### We looked at past research and found:

- Most research was set in care homes, there were hardly any studies in family settings and none in home care or hospitals.
- To reduce refusals of care, there was most evidence for:
  - **Playing recorded music during care**
  - **Different bathing techniques like strip washes or thermal baths**
- Controlling or patronising communication was more likely to create refusals.

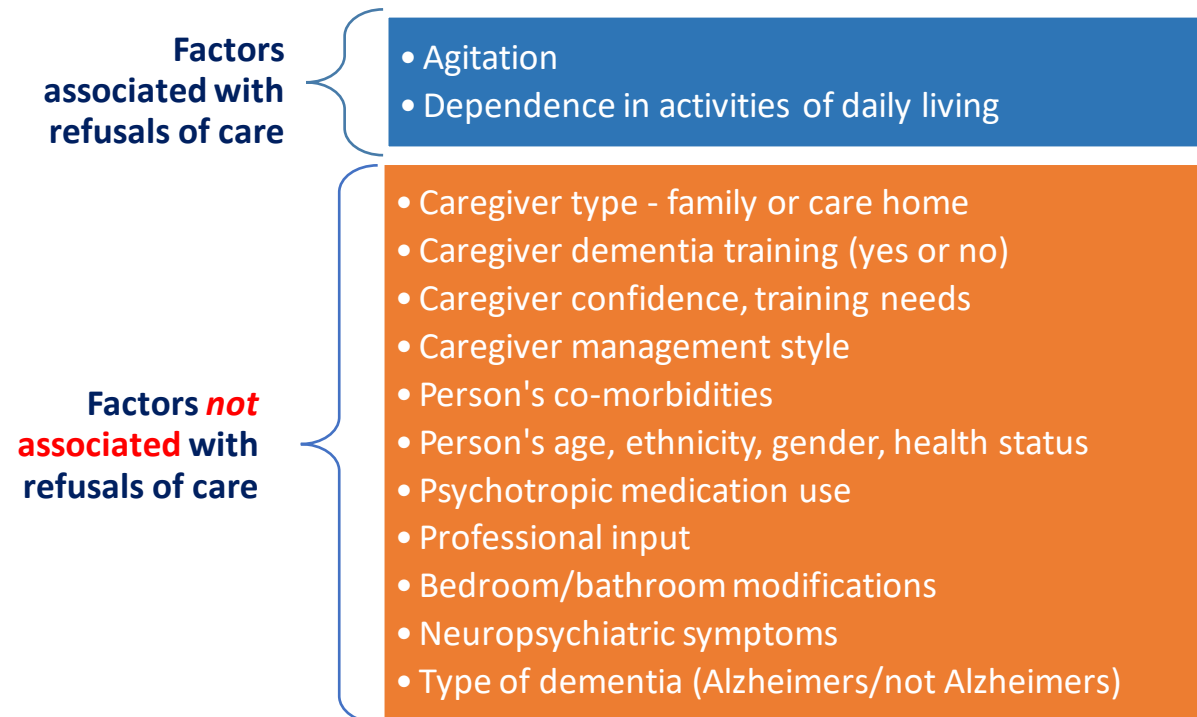
We interviewed 20 **family carers** and 12 **care-home staff** from 6 different care homes. We aimed to find out how caregivers managed refusals of care. We found out that the key strategies caregivers used were:



We interviewed 13 **people living with dementia** to find out about their experiences of receiving assistance with personal care. We found:



We recruited 130 **people with advanced dementia and their caregivers** (106 family carers, 24 care-home staff). We used questionnaires to ask the caregivers questions about themselves and the person with dementia they supported. Using these data, we conducted statistical tests to find out the factors associated with refusals of care in advanced dementia. We found:



We observed 14 **caregiver and person with dementia** pairs during 26 personal care interactions. We found most care interactions were positive events:

Positive care interactions	
<p><b>People with advanced dementia</b> Actively participated in care activities (for example, by lifting a leg or opening their mouth). Sought reassurance and guidance from caregivers.</p>	<p><b>Caregivers</b> Invited the person to be part of the interaction. Put the person at their ease . Guided the person through the care activity. Used the physical space and timing carefully.</p>
Difficult care interactions (these were rare)	
<p><b>People with advanced dementia</b> Were tolerating uncomfortable care. Struggled to get their perspective across to caregivers.</p>	<p><b>Caregivers</b> Became hurried or persistent. Had difficulties interpreting the person's communication.</p>