

What does 'neighbourhood' mean to carers for people with dementia: A multi- disciplinary study

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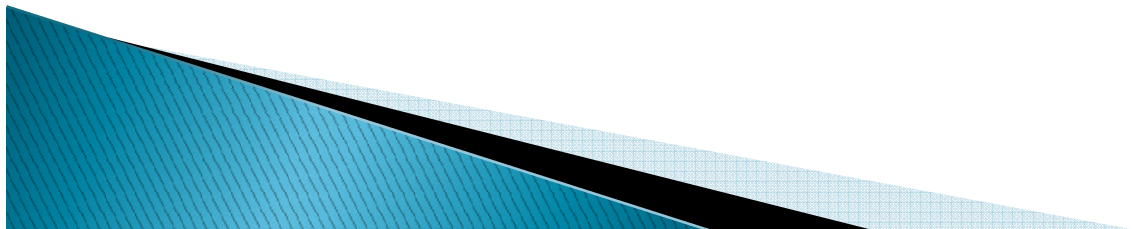
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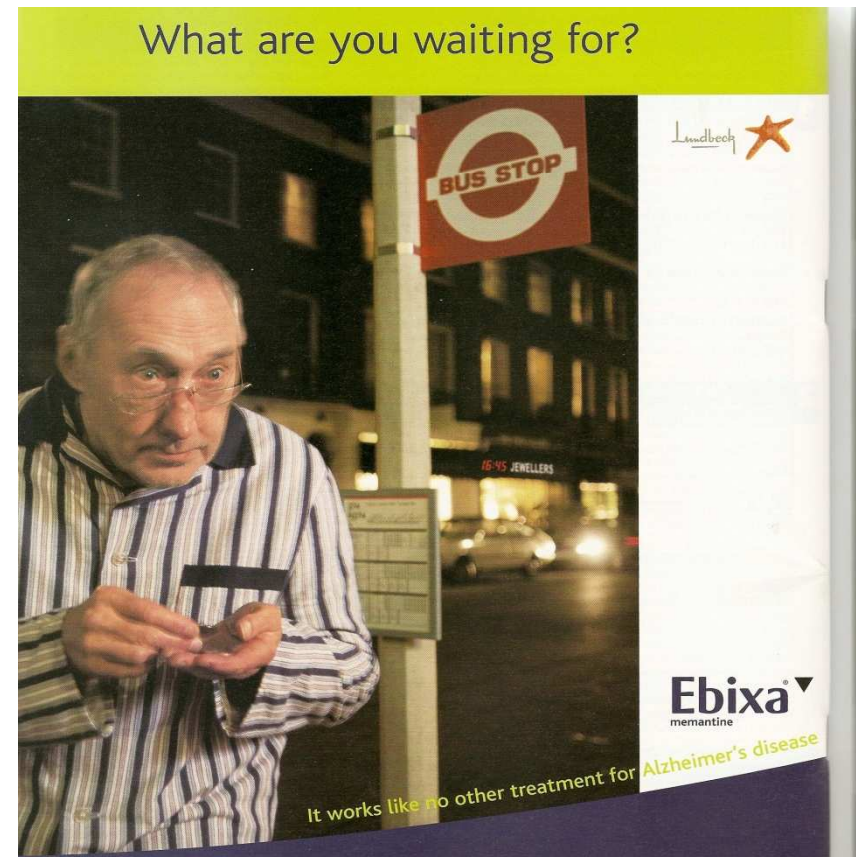
Prime Minister's Challenge on Dementia

“Building more dementia-friendly communities will take time. The Alzheimer’s Society will take the lead, working with members of the Dementia Action Alliance to create a formal dementia friendly recognition process that will make villages, towns and cities accountable to people with dementia and their carers through local Dementia Action Alliances. They will identify what villages, towns and cities need to do to be recognised as dementia-friendly. Only villages, towns and cities that meet their criteria will be granted dementia-friendly community status.” (DoH 2012)



Dementia and the outdoor environment

- ▶ Bio-medical model – ‘getting lost behaviour’ (symptomatic of dementia) The outdoors as ‘risk’ (e.g. McShane et al 1998)
- ▶ Social model
 - The dementia-friendly city (Mitchell et al 2003)
- ▶ A ‘shrinking world’ (Duggan et al 2008)



Project overview

▶ Research questions

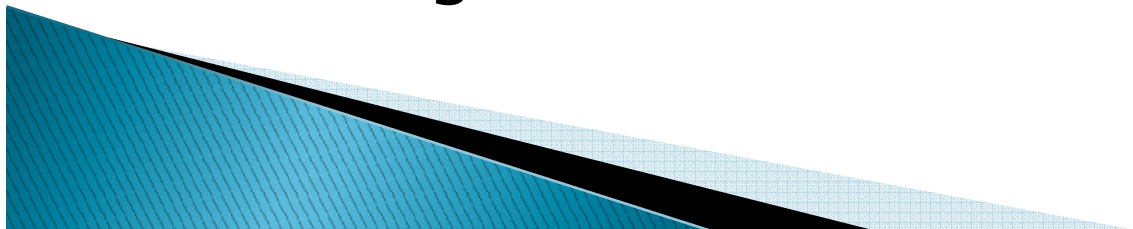
- How do carers for people with dementia use their neighbourhood and what does it mean to them?
- How can carers and people with dementia be supported locally and what can be done to improve this support?

▶ Sample

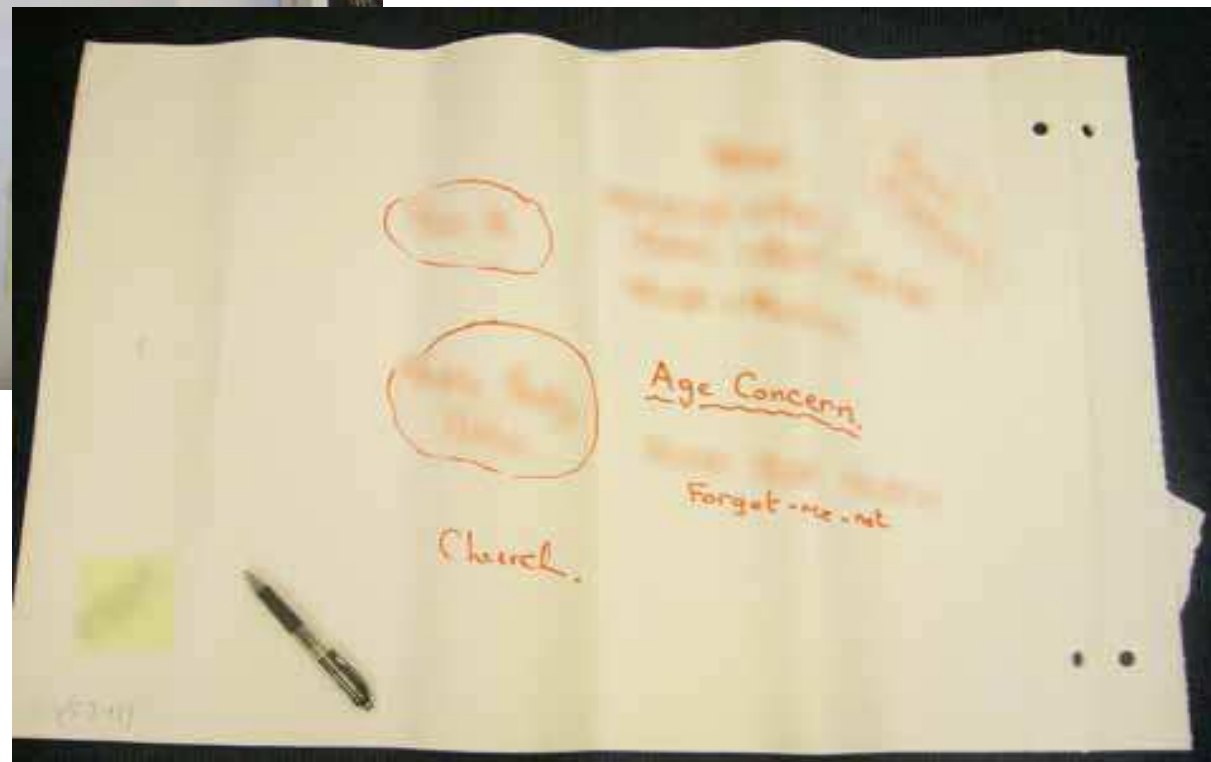
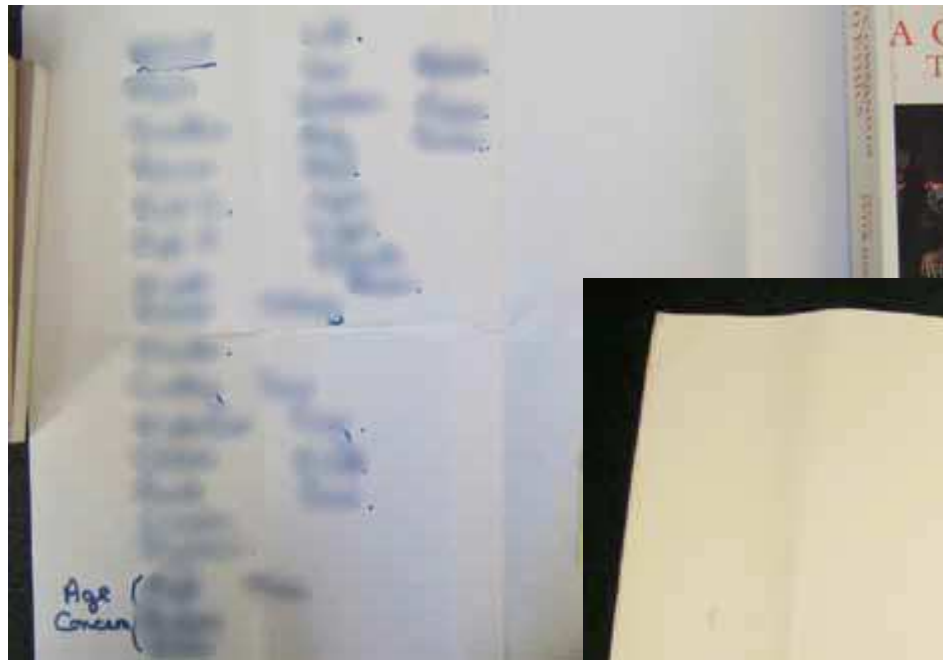
14 participants: 12 women/2 men; 10 Carers/ 4 Ex-carers

▶ Methods

- Discussion groups – Social network ‘maps’
- Walking interviews – Mobility diaries



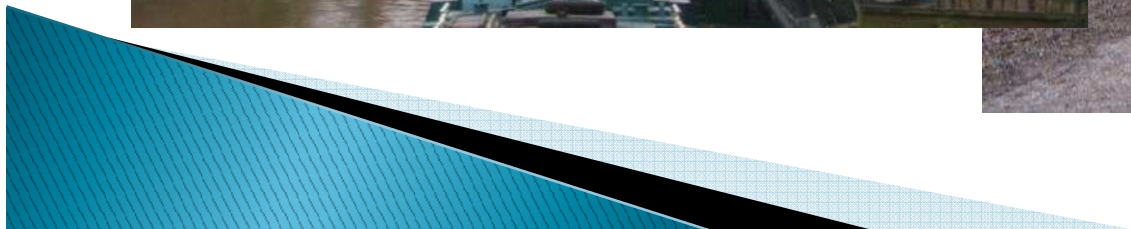
Social network maps



Walking interviews



Carers photographs



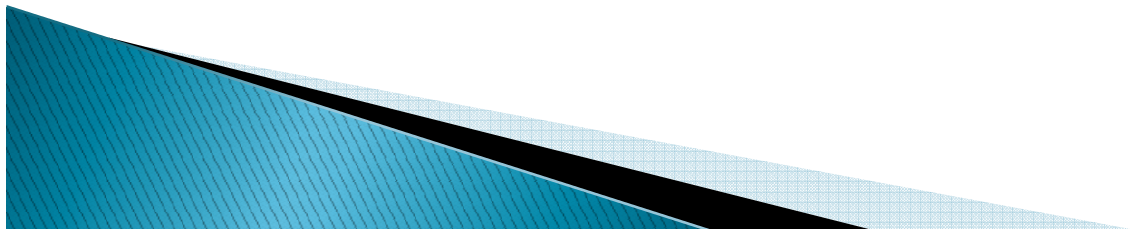
Findings – the changing meaning of home

“It’s when you go home. Then you feel isolated and you think there’s no one but you that’s in this situation and you’ve got to keep telling yourself ‘oh no, I was out this afternoon’, or ‘I was out yesterday’. Or ‘I’m going out tomorrow or the day after and am meeting people who are in the same situation’” (carer at discussion group)



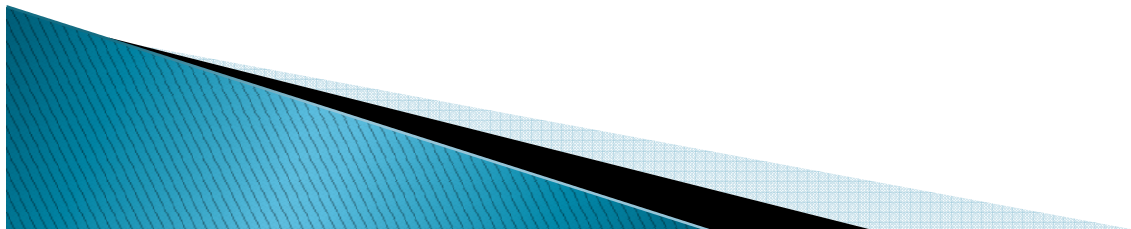
Getting out and about

- ▶ *If she sees it's nice and sunny she might want to go out for something to do... there's a coffee shop where we go in and the girls make a big [fuss], they love [her] you know, they think she's great you know, always seeing to her, and she wouldn't know them in the street (Male carer)*
- ▶ *We've got the cricket club further up which is very functional, very good, Dave is still a member because he enjoyed cricket, he's not able to go up, but he likes to be a member still, so it's there in his mind that when he feels like it he can go. (female carer)*



The importance of people close-by

- ▶ *I used to walk round with Dave and he got to know people, he can't remember them now, but he does know they're familiar and they'll say 'hello', and he knows then he's safe, because they're familiar looking... so that's his security (female carer)*
- ▶ *"...and you would turn around and he'd disappeared, you wouldn't know where he was and I found that going to all the same shops, I could say to the people 'has my husband been in?' Because they were used to it and they'd say, 'well' if he turns up, we'll send him to the car park' So I always knew, most of the time, when I got to the car park he was there" (discussion group)*



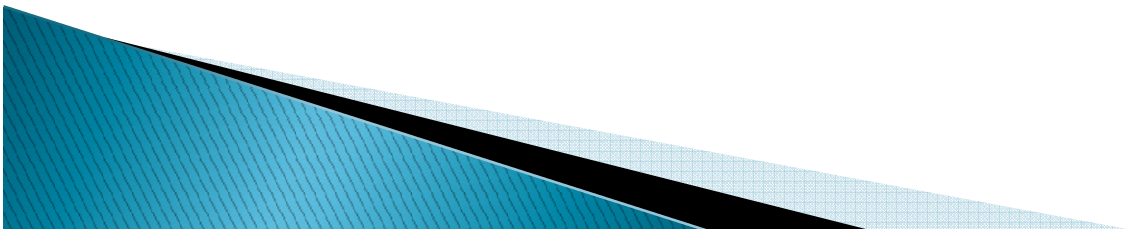
Reflections on inter-disciplinary working



‘Full-bodied’ research...

“...in 1966 the Queen visited Worsley and the powers-that-be thought the canal didn’t look very pretty, so they dyed it and it was the most awful shade of turquoise. And apparently the Queen, when she got out and went down to the canal, looked round and said ‘But I thought the water was brown?’ She had done her homework you see and found out about this and they had dyed the canal. It was about six months before they said.. it was horrible. It looked unnatural.

- *Did you go and see the Queen when she came to Worsley?*
- *Yes, yes, I pushed the pram. My daughter was 6 months old. It was the summer of 1966*



Communicating and disseminating

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Concluding thoughts

- ▶ Importance of consensus/agreement over the 'fundamentals' (not working across theoretical divides or paradigms)
- ▶ Introducing an openly reflexive approach (things worked for us but perhaps more by accident than design)
- ▶ Value of multi-sensorial approach (in this study multi-disciplinary also translated into multi-sensory/embodied ways of working)

