

# **The lived experience of the neighbourhood for carers of people with dementia**

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# A shrinking world...

*“A ‘shrinking world’ tends to lead to an overall decline in independence as places such as town centres become ‘no go’ areas, and even shopping locally often becomes dependent on being accompanied by a carer”*

**(Duggan et al 2008)**

*“Outside spaces can be anxiety-provoking (for both carers and people with dementia) leading to constraints on previous levels of outdoor activity”*

**(Brittain et al 2010)**

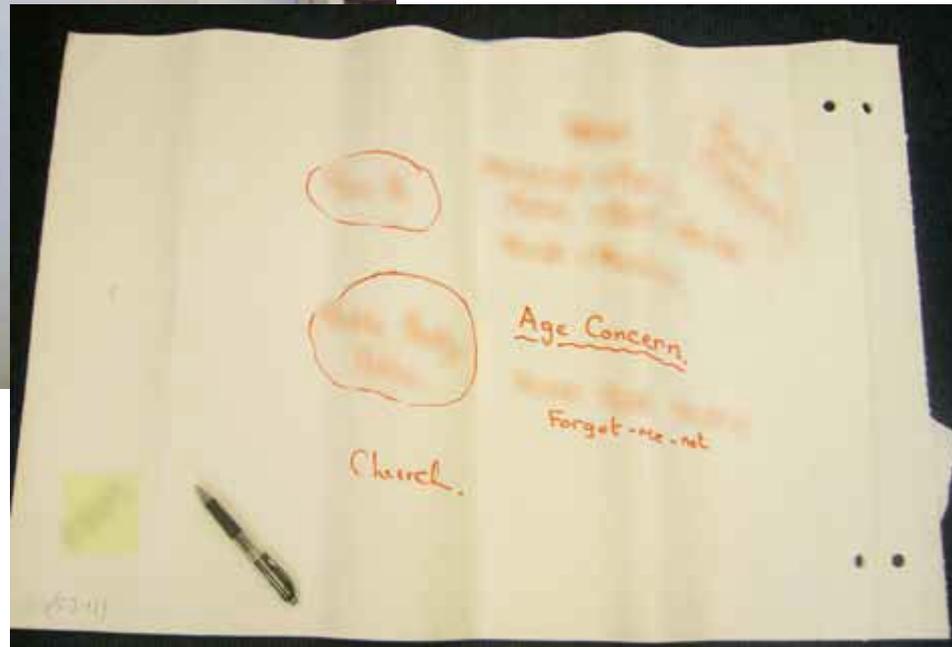


# About the project

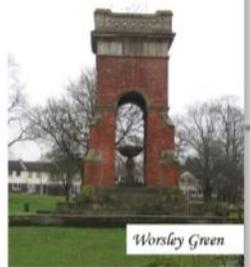
## Research questions

- ▶ 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?
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# Social mapping



# Walking interviews



# Changing meanings of home

- ▶ The home as a place of confinement

For people with dementia... *“John doesn’t go out as much now because the last time he did he decided that he would go for a walk, ‘I’ll just go round the corner’. The corner is right down the road. John doesn’t stop. John goes on. So about five hours later... I have to phone the police”*

For carers... *“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””*

# Why are neighbourhoods so important...?

- ▶ Neighbourhoods as ‘therapeutic places’
  - ▶ Safe spaces
  - ▶ Supportive spaces
  - ▶ Neighbourhoods and the collective capacity to care
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# Neighbourhoods as ‘therapeutic places’



*It just looks like a field to anybody else...*

Q: So you say this is a favourite walk?

Yes. Well I don't find there's an awful lot of places we can walk. ... I don't do it on my own because [he] comes with me, because I can't really leave him on his own... There's memories for me and [him], I tell him all about the past and you know, so he's involved with it... It gets all things, you know, all things -I don't know, memories for him. It brings him out and he just gets talking about things. I think when we're walking I don't know whether it just helps, but he seems to cotton on to things. You know, I'll say 'oh do you remember this at such a time or do you remember these sorts of trees' you know on holiday and different things... I jog his memory I think because then he starts talking about when he was a little boy and where they lived. ... When my mum was alive we used to walk it all the way through, cut through this football field. We used to do that with the children and grandchildren... It just looks like a field to anybody else, but it is nice... I think it's quite beautiful really.

# The importance of ‘safe spaces’

- ▶ *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 take a big, they love Sara you know, they think she's great you know, always seeing to her, and she wouldn't know them in the street but there she could*



*“Quite a few people go in [the pub]... That are [disabled] in some way or another, you know, not all with dementia, other things as well, and the staff there are, you know, they're very considerate with them”*

# The benefits of supportive spaces

“He used to go to Tesco’s a little distance from where we are and various members in Tesco got to know him and of course, if they saw him getting his shopping they’d make sure he’d put it in the bag and sort his money out and send him back home again..”

“...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”

# A collective capacity to care...

“I used to walk round with Jim and he got to know people, he can't remember them now, but he does know they're familiar and they'll say 'hello Jim', and he knows then he's safe, because they're familiar looking... so that's his security”

# Neighbourhoods, dementia care and policy implications

- ▶ Neighbourhoods are experienced as fluid spaces
  - ▶ Dementia care often operates in the spaces in-between the home and institutional settings
  - ▶ There are types of help and support currently overlooked by policy and practice
  - ▶ Dementia friendly communities are not simply about maintaining (physical) independence but about supporting identity and a sense of self
  - ▶ Neighbourhoods have a collective capacity to support people – the challenge is how to support and enhance this...
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