# 2 Experiences and Contributions of People Living with Dementia to the Social Life of Everyday Places

*Andrew Clark, Richard Ward, Sarah Campbell, John Keady, Agneta Kullberg, Kainde Manji, Elzana Odzakovic and Kirstein Rummery*



## Introduction

This chapter focuses on work programme 4 of the Neighbourhoods study entitled 'Neighbourhoods: Our People, Our Places'. We used a creative mix of qualitative methods, including network mapping, mobile interviews and home tours with people living with dementia and their care partners in England, Scotland and Sweden. We focused explicitly on the subjective meaning of neighbourhoods for people living with dementia with a view to understand how people could be better supported to live in community settings. Neighbourhoods matter to people with dementia because of the type of support they can offer, and this chapter presents insights into *how* and *why* this might be the case.

Neighbourhoods can enable people living with dementia to develop and sustain connections, maintain a sense of belonging, and contribute to the diversity and inclusivity of local places. Neighbourhoods are not simply fixed locations within which activities happen but are an amalgamation of connections to people and other places over time, understood and experienced in the context of other locations and times. Drawing on our published work (Ward et al., 2021a,b; Ward et al., 2022a,b), this chapter considers how people living with dementia are not passive observers of neighbourhood life but, instead, engage in the social rhythms of neighbourhoods and, with support, actively shape them as neighbourhoods of choice, though such choices are often restrained by contexts and circumstances.

The chapter is presented as follows. First, we provide a brief overview of some of the allied research that has explored the importance of neighbourhood spaces as sites for social interaction for people living with dementia. Next, it

outlines the ways in which we gathered and analysed our data. It then presents three interconnected 'key insights' of our findings, exploring: i) neighbourhoods as assemblages of connections; ii) neighbourhoods as real and symbolic sites of support; and iii) understanding neighbourhoods, dementia and change. The chapter then outlines how our findings might influence thinking about: neighbourhoods as relational places; how neighbourhoods might contribute to social health; and how people living with dementia can, with support, engage in neighbourhoods of choice. Collectively, these themes point to the relevance of understanding the 'lived neighbourhood' for people living with dementia.

Neighbourhoods matter to everyone. They are locations where people engage and interact with others, access retail, health and social care services, or leisure and workspaces. Perhaps most importantly, neighbourhoods also matter because they are locations where people spend much of their time, and this may be especially so for those living with dementia. Yet past research, as well as our own experiences, reveal disparities and inequalities in accessing, experiencing and benefiting from neighbourhood locations. These vary not just across different neighbourhood settings, but also vary by individual and household characteristics such as socio-economic status, gender, ethnicity and age.

As people age, we tend to spend more time at home and in environments close to home. Older people can remain more independent by, and benefit from, ageing in environments to which they are accustomed (Peace, 2022). This might be because of a familiar sense of place, attachment, belonging and control and how these might intersect with socio-demographic characteristics, physical and mental health, household composition, location and length of residence (Rowles and Bernard, 2013; Skinner et al., 2014; Peace, 2022). While it is important to avoid erroneously conflating growing older with dementia, it may be reasonable to assume that neighbourhoods might matter in similar ways to older people both with and without dementia, although with some notable differences. For instance, symptoms of dementia may impact on an individual's mobility or ability to communicate or create issues around memory. Living with dementia might also disrupt the spatial order of things being in place, and of knowing one's place within a locality (see for example: Bartlett and Brannelly, 2019). Despite this understanding, at the beginning of our study, there was a notable dearth of research insight into exactly how people living with dementia might experience and understand the places where they lived.

When reviewing existing work, we took our cue from Keady et al.'s (2012) review that identified three domains of activity: outdoor spaces, the built environment and everyday technologies (see Preamble and Overview at the start of this book). Of particular significance for understanding the subjective experiences of neighbourhood life was Duggan et al.'s. (2008) work reporting on the experiences of people with early to moderate dementia and their carers about the use of the outdoor environment. That study indicated that while people living with dementia valued the outdoor environment for providing access to exercise, fresh air, emotional well-being and informal encounters with neighbours and friends, they actually ventured outside less frequently as the symptoms associated with dementia became more pronounced. Duggan et al. (2008) used the phrase 'a shrinking world' to describe the processes by which people living

with dementia (and often their carers) withdrew into ever-decreasing social and physical worlds despite recognizing that maintaining external links was beneficial for health and well-being.

Over more recent years, additional work has emerged to understand experiences of dementia in neighbourhood contexts. Some of this continues to evidence the ways in which good environmental design can better support people and provide new insights into how people living with dementia interact with their immediate environments, further illuminating how neighbourhood settings can facilitate or impede life with dementia (Sturge et al., 2021; Baert et al., 2022). Developments in understanding the behavioural and psychosocial aspects of life with dementia also highlight how people living with dementia face barriers to accessing their neighbourhoods which, in turn, can negatively affect well-being or heighten feelings of vulnerability (Brorsson et al., 2016; Bartlett and Brannelly, 2019; Biglieri and Dean, 2021; 2022). Recent reviews of the field have acknowledged the complexity of neighbourhoods, such as how they might be defined, interpreted and experienced as psycho-social and material phenomena (Li et al., 2021; Seetharaman et al., 2021; Sturge et al., 2021), as well as the tendency of research to dichotomize physical and social environments (Gan et al., 2022).

In policy and practice fields, the potential for neighbourhoods to support people living with dementia has also become much more apparent (Hebert and Scales, 2017; McFadden, 2021). In the United Kingdom (UK), the development of 'dementia-friendly communities' formed part of a programme of packages and activities to support people living with dementia under both Prime Minister's challenges on dementia (Department of Health, 2012; 2015). While 'dementia-friendly communities' might be envisaged to encompass a diverse array of different amalgamations and groupings, including communities of interest and practice (Alzheimer's Europe, 2022), the spatiality and indeed 'localness' of the initiative, at least in the UK, has been apparent from its inception:

> *A dementia-friendly community is a city, town or village where people with dementia are understood, respected and supported. In a dementia-friendly community people will be aware of and understand dementia, so that people with dementia can continue to live in the way they want to and in the community they choose.*
>
> (Alzheimer's Society, 2022)

The neighbourhood, then, has been positioned as both an object for policy attention and a scale at which to deliver appropriate and timely support through organizations and agencies operating at a neighbourhood-scale. Still, despite such policy advances, how places can become more accommodating of people living with dementia, outside of any formalized or policy-driven initiative, remains unclear (Brittain and Degnan, 2022).

When we began our research, there was an arguably greater emphasis on the design and development of neighbourhoods as physical spaces, with less emphasis on understanding the support-giving, and perhaps even therapeutic qualities, of place to enable people to get on with a life with dementia. What was less developed at the time, and which we were able to begin to explore

through a pilot project that became a precursor to 'Neighbourhoods: Our People, Our Places' (Ward et al., 2012), was understanding neighbourhoods from the perspective of those living with dementia themselves. It was these more subjective, finely grained insights into experiences of place that accumulate at the particular scale of the neighbourhood that our research focused on.

## Study design

### Research question, study aims and objectives

As just shared, the study design was based on a successful pilot project undertaken by two of the research team and authorship, Richard and Andrew (see: Ward et al., 2012). This exploratory work provided an opportunity to trial various methods of data collection, explore substantive issues, understand how better to involve people living with dementia in research about neighbourhoods, and engage with stakeholders, including those living with dementia. Our pilot project conducted in Greater Manchester in northwest England informed our view that we should not so much focus on the design of places, or on interventions to make places more 'dementia-friendly', but on the multifaceted ways in which everyday encounters and interactions make up everyday life in local places.

Our intention was to investigate how neighbourhoods and local communities can support people living with dementia to remain socially and physically active. We approached the idea of the neighbourhood as an amalgamation of social, biographical and physical constructs and were interested in how these dimensions intersected, and impacted, on the life and care of people living with dementia and those who cared and supported them. By considering the neighbourhood over time, we also set out to understand how changes for a person living with dementia, and changes to neighbourhoods, produced different experiences and opportunities.



### Methodology and methods

Working within a social constructionist paradigm, we used three qualitative methods framed by a longitudinal and comparative design to understand how participants experienced, described or demonstrated what their neighbourhoods meant to them. First, we used walking interviews in which people living with dementia and sometimes their family carers took us on a 'neighbourhood walk' to show us around their local area. Here, discussion focused on memories of living there and of their connections to place (Kullberg and Odzakovic, 2017). Second, and considering home to be the starting point to a neighbourhood, we encouraged participants living with dementia to lead us on a filmed tour around their home (Pink, 2007). Third, we used a participatory social network mapping technique to explore with family carers and people living with dementia (whenever possible) the relationships that they have in their everyday lives and to consider how those relationships might offer opportunities for support, interaction and engagement (Campbell et al., 2019).

**Table 2.1** Aims of each method

| |
|---|
| **Walking interview**<br>• To understand how individuals conceptualize their neighbourhoods.<br>• To understand how individuals articulate these neighbourhoods verbally and through spatial practices.<br>• To understand the situatedness of an individual's network through exploration of how it is constructed through (local) places. |
| **Home tour**<br>• To understand how individuals conceptualize their home environment and where it is.<br>• To understand how meanings of home change for individuals and how this may be affected after a diagnosis of dementia.<br>• To understand how the home environment supports or disrupts the experience of dementia or how it is adapted and impacted upon by the experience of living with dementia.<br>• To provide an approach that allows individuals to participate in telling us about their homes and what is important to them about home.<br>• To understand the sensory, materiality and social elements that create the home-place-event.<br>• To understand the situatedness and fluidity of home over time and how external influences have an effect on home and its meanings. |
| **Social network map**<br>• To understand how individuals conceptualize their social networks.<br>• To understand how individuals articulate these networks in verbal and diagrammatic forms.<br>• To provide an approach that allows individuals to describe the practices by explaining what happens between individuals and groups of individuals in their network.<br>• To understand the relationality of an individual's network through exploration of how members within it are linked to each other.<br>• To understand the situatedness and fluidity of an individual's network through exploration of how an individual's network is constructed over time. |



The network map and walking interview were completed at two time points to enable appreciation of how someone's understanding of, and engagement with, neighbourhoods change over time. The home tour was completed once, unless a participant had moved homes since our previous encounter, when they had the opportunity to take us on a second tour. In addition, a small number of participants chose to keep a diary of where they went or who they met over a short period. The aims of the three main methods are detailed in Table 2.1. In using different methods in this way, our intention was not to triangulate the data or seek out a more accurate understanding, but, rather, to appreciate the different facets of life with dementia. In developing participative methods, we also hoped to support people living with dementia to reveal their relationship to neighbourhoods in their own ways.

## Sampling structure

Data was collected in three distinct locations: Greater Manchester; the Central Belt of Scotland; and the county of Östergötland in the south of Sweden. Participants were recruited mainly through third sector (voluntary) support groups in Scotland and England, and through health and social care services in Sweden. The scope and scale of the data collected is detailed in Table 2.2. In total,

**Table 2.2** Participants relationship/household structure and data collection by field site

| | | England | Scotland | Sweden | Total |
|---|---|---|---|---|---|
| Participants | Total | 54 | 47 | 26 | 127 |
| | Living with dementia | 29 | 22 | 16 | 67 |
| | Nominated care-partner | 25 | 25 | 10 | 60 |
| | *Of whom...* | | | | |
| | Were living in a couple dyad | 50 | 32 | 20 | 102 |
| | Were living alone | 4 People living with dementia | 6 people living with dementia; 9 carers | 6 | 25 |
| Age (of person living with dementia) | Youngest | 57 | 51 | 62 | |
| | Oldest | 88 | 88 | 87 | |
| Methods | Network maps | 53 | 55 | 30 | 138 |
| | Walking interviews | 41 | 40 | 18 | 99 |
| | Home tour | 30 | 29 | 0 | 59 |
| | Other | 2 mobility diaries | 5 mobility diaries 1 day diary | 0 | 8 |
| | Total | 126 | 130 | 48 | 304 |

127 individuals participated across the three locations, 67 of whom had a diagnosis of dementia and 60 self-identified as a carer. The age of participants ranged from 51 to 88 years. We strove to go beyond the potentially homogenizing category of 'people living with dementia' to understand the experiences of those who lived alone and (albeit indirectly through the experiences of carers) living in care homes, as well as drawing insights across age, gender, and different types of neighbourhoods.

For interest, Figure 4.1 in Chapter 4 also includes a visual overview of the methods used in this study.

### Data analysis

Our analysis drew upon the multiple data sources to emphasize the multidimensionality of a person's experience of their neighbourhood. Using a facet methodology approach, the data was interrogated along question-driven or insight-driven routes across and between the facets (Mason, 2011).

Throughout the research process we aspired to a collaborative approach, working alongside people living with dementia and their care partners. This included design and dissemination phases. People living with dementia were involved at various stages of the research, including input into recruitment, development of methods, production of participant information and by contributing to the emergent analysis. Alongside more conventional academic activities, such as conferences and published outputs, we developed a collaborative programme of knowledge exchange to engage the wider public in debate about the purposes that neighbourhoods and local communities can, and should, play in supporting people living with dementia. These included engaging with people living with dementia, health and social care professionals, and third sector organizations to support neighbourhood-based initiatives to encourage connections and interactions. We also worked with a group of people living with dementia and an artist to produce a series of illustrated magazines (sometimes referred to as 'zines') to promote the research findings.



### Ethics approval

Ethical approval was obtained for the research across all three settings via the applicable ethical governance systems in each locality, including the relevant NHS health and social care panel in England. In keeping with the study protocol, all names reported in this chapter are pseudonyms.

## Findings

The full results of the research have been presented in academic journals (see for example: Ward et al., 2018; Odzakovic et al., 2019; Clark et al., 2020; Clark et al., 2021; Ward et al., 2021a,b; Ward et al., 2022a,b). In this chapter, we provide an

overview of insights from the work and synthesized key insights we have explored in more detail in other outputs.

### Key Insight 1: Neighbourhoods as assemblages of connections

Alongside the locations for transactional activities such as accessing retail and cultural offers or health and social care, participants were keen to explain the ways in which neighbourhoods reflect assemblages of connections to people and places over time. Neighbourhoods are more than environments within which people move around. They are places where social connection, inclusion and support are thus experienced as relational, dynamic and fluid. They are not, then, static or immune to change, but are shaped by people and their practices (Andrews et al., 2007; Ward et al., 2018; Clark et al., 2020).

Participants described a rich and diverse array of connections beyond family and friendship circles that are mediated through neighbourhoods, and which give meaning to neighbourhood locations not as 'spaces' but as 'places' replete with experiences. Focusing on one group by way of example, neighbours were described as people with whom participants were not overly familiar, but could provide practical assistance and ongoing reassurance. This ranged from the security of a 'watchful eye' to practical input to the relatively mundane chores associated with small favours, such as helping to manage household refuse or keeping an eye on gardens and properties when left unattended (Clark et al., 2021). While articulating the precise differences between categories of people was often tricky, participants were able to recognize nuanced differences and how these differences were important in getting on with life. For instance, the difference between neighbours and friends was determined not only by the role they played, but also by subjective and contextually defined degrees of intimacy as Adam, who lives with dementia, and Pam, his care partner, shared:

*Interviewer:* *…and have you got to know any of your neighbours here?*
*Adam:* *Oh yeah.*
*Pam:* *Either side we know reasonably well, and we know probably most people who live along this road, but no…obviously we're able to say hello and have a, kind of, just a general chat, you know, it's not close friends, we've left our close friends behind.*

This recognition without intimate familiarity underpins that good neighbourly practices produce a somewhat taken-for-granted social order that has been acknowledged in earlier studies of neighbouring (Wenger, 1984; Bulmer, 1986; Crow et al., 2002). Saying 'hello' or just 'having a chat' reflect a shallow level of intimacy that nonetheless offers an important way of binding people to others in place and supporting a sense of belonging. Margaret, who rarely left her home, described not seeing her neighbours very often because their neighbourhood rhythms were not in sync. Many of Margaret's neighbours were working full time and caring for children and other family members, just as she had done in the past. As a result, Margaret, who lives with dementia, and her

neighbours rarely crossed paths. Nonetheless, every week, her neighbour would pop round to help her take out her household rubbish/recycling, as Margaret explained:

> *He knocks on the window, I'm usually sat in the front room with the telly [television] on and he'll knock on the front window. He'll say [hello]. I might never see him from one day to the next, really.*

As acts of support, such gestures are not the most important that participants living with dementia receive. Indeed, they arguably amount to very little in terms of the quality of the interaction, but their significance does not lie in the outcome of the transaction or its frequency or extent. Rather, such actions take on a particular symbolic quality through their implied, as well as realized, sense of being connected to others. Such interactions and connections derive their significance then from their potential to reflect both real and symbolic support.

### Key Insight 2: Neighbourhoods as real and symbolic sites of support

Connections with neighbours and other local figures can provide a form of latent support – something that is present but not necessarily active outside of certain conditions. As Wiersma and Denton (2016) have suggested, such connections can act as a safety net to fall back on in instances where assistance is required. This is one reason why the connections with others in the neighbourhood can have an almost potent significance as Frank, care partner to Suzanne who lives with dementia, suggests:

*Frank:* *There are people down the road that I could call upon if I needed some help, yes.*
*Interviewer:* *So if there was an emergency…*
*Frank:* *Oh, yes.*
*Interviewer:* *Or something like that there'd be someone you could call upon?*
*Frank:* *There's [a neighbour couple] down the road who we've known ever since we moved in.… Then a bit further down is [another neighbour] and we've known them for probably 15, 16 years, I think.… If I was to ask them they would do anything for Suzanne and I know I can call on them if need be. My circle of friends is [small]… It's my own fault, I don't make the effort really for going out. So there are lots of people that I could call upon, but in terms of social interaction, I don't do much.*

We can see in Frank and Suzanne's comment some elements of how connections with others can diminish over time (Duggan et al., 2008). We are not suggesting that connections with neighbours replicate or replace other, perhaps 'stronger' (Granovetter, 1973) ties to family or friends, nor imply that the boundaries between each of these relational domains is clear. What is more important is how Frank and Suzanne's local relations can endure as weak ties – perhaps rarely

acknowledged – in ways that can be just as crucial in certain undetermined circumstances as other connections. It may be that the persistence of neighbourly relations for Frank and Suzanne is the result of longstanding interactions and the accumulation of loyalty. However, experiences from other participants who describe similar relations with neighbours formed over considerably shorter periods indicates that length of association with place is not necessarily the underlying factor.

We are mindful here to avoid perpetuating a somewhat nostalgic narrative that suggests that, provided people living with dementia maintain some kind of connection with their neighbours, then they will be able to participate fully in a life devoid of worry, stress or challenge. We are also critical of common narratives about the decline of neighbourhood communities; of the loss of tight-knit, locally situated relationships of an unspecified past 'golden era' when seemingly everyone in the street looked out for everyone else. Indeed, gender, ethnicity, co-morbidities and indeed, choice, will all impact on the extent to which someone may interact with those who live nearby. Rather, what we take from participants' accounts are the ways in which these relationships are maintained through locally situated, routine practices. These in turn provide opportunities for support through a sense of familiarity and recognition facilitated by being in familiar places at particular times.

Our data shows that it is not only neighbours who can provide low order support. Anna, who lives alone with dementia, told us about an arrangement with a public house close to her home:

*Anna:* *Here, there's a very nice…they make dinners, and I take a lot of my dinners in there, and they make…they have music and things like that, they're really nice people.*

*Interviewer:* *And have they got to know you a little bit?*

*Anna:* *And they have, they've taken me on a bit… I tell them what I've had and they keep the money, and then we pay them at the end of the [month].*



This arrangement was also described by Anna's adult daughter:

*Daughter:* *There's several pubs she's got to know, a little network of pubs. If I want to find my mum, not because she's an alcoholic, but they all know her. I go, 'Have you seen her today?' They go, well, 'She was here earlier, I think she went'…if I can't find her, which can be a problem in the afternoon when we…the afternoon appointments are difficult.*

*Anna:* *I do pop in and see people and quite a lot of people know me now.*

*Daughter:* *… you've built up a real network of people. If we're in the supermarket down there, or the little shop, they always come up and say, 'Hi Anna,' and you go, 'I don't know who that is'… There's the [pub] here, because the [bank] card…we've had problems with the [bank] card and money is quite a problem. A few times … you*

> *were using contactless with the [bank] card but then every so often they ask for a [pin] number… So we came to this agreement where I would put money, they said I could pay every Sunday and I said, 'Well, that's just going to add to my list of responsibilities, really.' So I said, 'Could I not just pay ahead?' So now I just go and put money on a tab.*

We can see here how a local outlet (in Anna's case a public house or 'pub') can become a part of a wider network of support outside of any formal arrangement. The public house involved here was not part of any formalized 'dementia-friendly community' initiative. Rather, Anna, Anna's daughter and staff recognized a way in which they could continue to support Anna to independently enjoy relatively simple activities. What makes the arrangement workable is the trust that developed between them, and which afforded an atmosphere where a disclosure of a diagnosis of dementia could legitimize action. Crucially though, the arrangement is reproduced by Anna herself through her own temporal and spatial practices; of being in particular places at particular times. This sort of support does not happen in isolation from its wider context, and Anna's positive experiences here are enabled by a familiarity that can be achieved by her being able to take habitual trips out of her home to connect with others. This is something that not all participants were able, or perhaps wanted, to do, including those who live alone (Odzakovic et al., 2019; and see Chapter 4). However, our data indicates that even short opportunities to routinely get out and about can provide occasions for small acts of support and care that can maintain connections and a wider sense of belonging.

The neighbourhood interactions and relations we have described here cannot address the challenges of living with the symptoms of dementia in isolation or replace statutory or third sector support. They can, however, play a role alongside support networks, formal care and individual efforts and abilities, and these are dependent on how neighbourhoods exist as social spaces. Here, different neighbourhoods will be more or less able to support interactions – some may lack sufficient or appropriate infrastructure to facilitate connections because of the absence of appropriate businesses or services, poor design, lower population densities or socioeconomic deprivation, and all this can vary over time (Ward et al., 2022a,b). Thinking that engaging and interacting locally can lessen the symptoms of dementia, as well as overcome the structural inequalities that impact on people's experiences of place, also risks perpetuating an environmental determinism about the capacity of neighbourhoods to influence life outcomes. It also, as we now consider, risks perpetuating a nostalgic and romanticized discourse of neighbourhoods (and those who live and work in them) as being ever-present and unchanging when all this is in a constant state of flux.

### Key Insight 3: Understanding neighbourhoods, dementia and change

Our final insight addresses how we might understand neighbourhood change in the context of dementia. We know that symptoms associated with dementia can

develop and change over time. Many participants were aware that they recognized the value of living 'in the moment', articulating their awareness that it may not always be possible to maintain some of the practices that seem so important. Emily, who cared for her husband Dylan, talked about future anxieties about him going out alone:

> *I mean it will [become a worry in the] future when I know that perhaps he shouldn't be doing things like that and I'm not going to be able to stop him. I don't know what I'll do. I'll just cross that bridge when I come to it, I suppose. Yeah. I mean, at the minute he doesn't get lost but very often he can't now tell me the route he's taken… But we've always lived in this area and he's always cycled and run in the same area, so he's still using the same routes…So they're very familiar to him.*

Mirroring points discussed above, traversing a regular route, combined with a familiarity achieved by living in one place over a period of time, provided opportunities for Dylan to continue to still get out and about independently. Still, these may not be sufficient to support him to continue to leave his home alone in the future, or at least may not prove successful every time he does so. Neighbourhoods are '*dynamic landscapes of social, political, cultural, and personal change*' (Andrews et al., 2007, p.157) and this dynamism inevitably impacts on those living with dementia. We witnessed, and were told about, some of these changes throughout the work; shops and services open and close, neighbours come and go, and the physical environment can be altered. As Cecilia, living alone with dementia described, sometimes the most mundane of changes can fleetingly disrupt a person's sense of belonging to place:

> *When I moved here, it was summer and from time to time there were so many children, who all lived in my courtyard …and then the lady who lives above me, we know each other a bit because we both worked at the same workplace, so we usually talk. During our conversation, I just said: where did all the kids go? They were so lovely, funny, and just sitting there…and look at how they were playing and laughing, it was a pleasure. Then, my neighbour told me that the parents of the children have bought a house on the other side of the street. That's lovely, but I miss the kids.*

What matters here is Cecilia's ongoing ability to feel connected to others, be that through recognizing people on the street or seeing familiar faces through a window or over a garden fence and offer a sense of belonging to a world beyond the home (for an extended discussion see: Odzakovic et al., 2021 and also Chapter 4 in this book). For those who experience symptoms that limit their ability to get out and about, opportunities to connect through and beyond the home were particularly valued. As we also noted in Odzakovic et al. (2021), being able to look out on the world through a window can enable a sense of connection to life outside, offering a temporary release from the difficulties associated with staying indoors.

This starts to point to how neighbourhoods are not fixed but configured through particular arrangements of people, place and practices in time and space. When neighbourhood changes coincide with fluctuations in experiences of dementia, this can prompt a need to adapt strategies to get out and about, as this lengthy exchange between Albert, who lives with dementia, Vera, his care partner, and the interviewer (a member of the chapter authorship), indicates:

*Albert:* *The newspaper shop which I used to go to at the top of the road…*
*Vera:* *Oh that was great. It's closed now, they knew him very well there … [comment directed towards the interviewer].*
*Albert:* *They knew me and I knew them, I could stop and have a chat with them, you know.*
*Vera:* *And then when he'd done that, he'd walk down to [daughter]'s grave, see if the flowers were alright.*
*Albert:* *Yeah, I'd walk down from the corner, because it's behind there, the shop, there's the graveyard where [name of daughter] is, my daughter is buried and I used to go up there.*
*Vera:* *Now there's two major roads to cross, so he doesn't go quite as often, which I don't blame him, you know, it's a bit too much that.*
*Interviewer:* *Yeah … so do you miss going up there?*
*Vera:* *Not now, he goes to the garage [petrol station].*
*Albert:* *Well I do call in occasionally…I used to go every day when the paper shop was there, but it's gone, that's gone now.*
*Vera:* *And I don't want him to stop going, I want him to, you know, make sure that he can still go out, even though he's got his identity [card], make sure he's got his identity [card] in his pocket, just in case he gets lost, you never know.*



Participants anticipated, and prepared as best they could, for future changes in active ways as we discuss in more detail in Ward et al. (2022a). Some made efforts to build some resilience into established networks, such as Albert's example of care passing between shop staff. On the one hand, this may be dependent (like Anna's example earlier) on a willingness to disclose a diagnosis, as well as an ability to continue to maintain regular neighbourhood practices such as using a regular bus service or frequenting particular shops. On the other hand, none of these actions are always possible as John, who lives with dementia, observed:

> *I went into the local shop. I go in there for a paper. They always say 'How are you John?' I said 'I'm going to tell you that I've been diagnosed with dementia'. 'Oh God' she says, 'that's a shame'. 'Well' she says, 'I'll have a talk to the girls and tell them to look after you'. I thought it was awfully nice you know. Some staff left two weeks ago, and yesterday I went in and it was a lassie that had just started, you know, and I said 'Good morning, I want this'. She says 'Good morning John, how are you today?' And I thought God, it's carried on, you know. She's told everyone and said 'you look after him' you know.*

There are echoes here of how frequenting local shops might enable people to remain socially connected and of how assemblages of services (retail, cultural and support) and people in places/neighbourhoods can provide some consistency of support as well as opportunities for ongoing social participation. Like John, many participants experienced moments when they struggled to perform certain tasks in public. In response, some described how they would disclose their dementia diagnosis to staff as a way of seeking support, but also to bring into the open something that might otherwise be left hidden or unsaid. A few had also become involved in local 'dementia activism' to ensure that retailers and others could support them by creating a welcoming atmosphere (Ward et al, 2022a).

As we explained in Ward et al. (2022a), participants formed newer connections with others affected by dementia. In this context, service providers (especially local voluntary sector organizations) played a crucial role in helping people living with dementia to find one another and help to establish new neighbourhood connections. This focus on neighbourhood practices, rather than the materiality of the (built) neighbourhood, makes it possible to understand how neighbourhoods are always being remade and suggests how modest modifications to locally situated social practices might offer opportunities for ongoing engagement. Such modifications can range from how people manage strategies for getting out and about to frequent local shops, to engaging in acts of neighbouring, to being able to access a view through a window. Rather than a closing or a cutting off connections and interactions, we see a shift in how these connections and interactions are conducted. So, it is in these seemingly trivial ways that we can begin to see how some of the determinism of a 'shrinking word' can be disrupted in ways that hint at an alternative to an 'impairment-led' explanation for the relationship between people living with dementia and their neighbourhood.



## Discussion

We did not set out to develop a definitive account of what neighbourhoods mean for people living with dementia. However, our data points to ways in which the work might inform wider debates about local places in the context of dementia.

First, and echoing relational accounts of place offered elsewhere (e.g., Andrews et al., 2013), neighbourhoods are a people-place-biography nexus (Ward et al., 2021b; Ward et al., 2022a). Relational understandings consider place as always in a process of becoming and the product of materially embedded practices and relations. Rather than being the 'receivers' or even the 'experiencers' of neighbourhoods, people living with dementia enact a myriad of processes that contribute towards their production. Neighbourhoods are not only locations that are entered and then left to undertake some form of transaction, for example to access a shop or organization. They also offer

opportunities for social practices that provide a social infrastructure (Yarker, 2022). This enables people living with dementia to participate in activities and relationships through engaged citizenship.

Neighbourhoods mattered to those we spoke to so long as they were able to keep up regular and routine presence within them. This was achieved through the assembling and layering of a collection of routines and habituation; of patronising particular shops; recognizing and being recognized by others on the street; making fleeting connections via a wave through a window or across the street; and the embodied undertaking of repeated journeys along regular routes. As one-off events, such activities are arguably of limited significance, but when undertaken as habitual practices over time in the same places, they create opportunities for ongoing relational connection.

It is this processual understanding of neighbourhood, achieved through the layering of everyday practices, that actively shape what we might call the lived neighbourhood (Ward et al., 2018). Participants' engagement in such practices, for example getting out and about, greeting and being greeted by others, and receiving and reciprocating acts of care and kindness, indicate how engaging in the social life of local places has the potential to influence personhood and relational citizenship through communication and engagement (Li et al., 2021). Drawing on Massey's (2005) ideas about relational geographies, elsewhere we have posited that neighbourhoods are sets of practices within particular time-space framings (see: Clark et al., 2020; 2021). Rather than experienced as a metaphorical 'container' within which people get on with life, a neighbourhood is experienced as a series of expanding and contracting connections to people and places accessed through more and less familiar nodes. Seen in this way, neighbourhoods are not stable locations with fixed boundaries that can be tweaked or improved, for instance to be made more 'dementia-friendly' for those who enter them. Instead, they are networks of social practices, interactions and engagements that enable people living with dementia to actively participate in the construction and maintenance of connections to people and places.

Second, a focus on neighbourhoods can contribute to how we understand the social health of people living with dementia (Ward et al., 2018). Social health has been informed by understanding of how the social domain can influence one's health, including a person's capacity to fulfil their potential and obligations, the ability to manage life with some degree of independence and the ability to participate in social activities (Huber et al., 2011). Vernooij-Dassen and Jeon (2016) have argued for the importance of recognizing the social health dimension in the context of dementia by '*making a dynamic balance between opportunities and limitations, affected by external conditions such as social and environmental challenges*' (p.701). The relationality we have described in this chapter shows how neighbourhoods are part of this dynamic, mediating between inclusion and exclusion in seemingly mundane, but far from trivial, ways. Being able to participate, in whatever capacity, in the social life of neighbourhood spaces, provides people living with dementia opportunity for social engagement. Meanwhile, receiving and reciprocating acts of kindness and care among neighbours in routine, but frequently unabetted, ways reveal how

neighbourhoods provide scope for meaningful social practices. These practices do not replace more wide-reaching support, such as financial and personal care, but that is not the role of such interactions and practices in the wider web that makes up an individual's social health.

Finally, the data shows the agentic capacity of people living with dementia in neighbourhood spaces. Neighbourhoods are constructed and reproduced by institutions, social groups and individuals operating within underlying structures. People living with dementia should be enabled to participate in the full gamut of neighbourhood practices in this process, not just as advocates or consumers of 'dementia-friendly communities', but as individuals who have the right to be seen in, and engage with, local places. Still, those who experience mobility challenges, have difficulty remembering routes, or who find themselves disorientated in public spaces, can find themselves very much out of place in locations that they might have long association with. This may lead to a sense of estrangement, especially if people recognize their difficulties maintaining certain practices (Clarke and Bailey, 2016; Bartlett and Brannelly, 2019). As such, rather than a quality of neighbourhood living, familiarity is an achievement enacted through locally situated practices in a 'lived neighbourhood' (Ward et al., 2018; 2022a).

There are, perhaps, discursive parallels to be drawn here with the idea of elective belonging. Elective belonging has mostly been used to critically explore how people attach their residential biography to a chosen location despite having no prior ties to it and express their social identities through where they live (Savage et al., 2005). The term has been proposed as an explanation of how place might be experienced through a social class lens to encapsulate how, through the working of Bourdieu's idea of habitus, people form bonds of belonging and spatial attachment via social networks and connectivity and the deployment of various capitals. As Jeffery (2018) explains, at the heart of elective belonging is an understanding of how different forms of socialization and social, human and cultural capital are deployed through space to enable someone to choose to belong to a (residential) location. We are not advocating the uncritical transfer of the ideas about elective belonging to our findings, but we can arguably see traces of these processes in the data. For instance, the sense of dislocation some participants may have described was facilitated not only by physical neighbourhood change, but also by discourses around people living with dementia becoming at risk of becoming excluded from neighbourhood spaces where they no longer felt they belonged, and felt they possessed little agentic capacity to remedy of resist this.

Becoming disconnected, or disengaged, with wider networks or locations may have thus led to some people living with dementia to feel alienated from locations to which they had previously felt attachments. Critically though, such discourses are countered by a myriad of experiences that were relayed to us, including through the ways in which networks and connections can help people to elect to belong. People living with dementia work to resist, albeit in small and, at times, rather mundane and perhaps even unremarkable ways, dominant representations of dementia. In this way, we have shown how neighbourhood

practices are at the forefront of ongoing attempts to not only bring about more inclusive neighbourhoods, but also might counter competing views of life with dementia.

Supporting people living with dementia to belong in their neighbourhoods in whatever ways they feel able to echoes an ethos of personhood that prioritizes the individual over their dementia. As we have described in this chapter, neighbourhoods are more than the containers of potentially hazardous or risky features and activities in need of being made 'friendlier' through removal, or modification, before those living with dementia can be trusted to venture into them. They are instead locations where people living with dementia engage, connect and have attachments, provided they have appropriate support to do so, and this support can take many forms. This does not mean that neighbourhoods are risk free, experienced in the same ways by everybody, or are currently equally accessible to all. There is much work still to be done to ensure ongoing, equal engagement in neighbourhood practices, but we hope that the work we have done on 'Neighbourhoods: Our People, Our Places' has taken a small step in this direction.



## 'So what?'

- If you are someone living with dementia then people we spoke to in our work found that keeping up habits and routines to stay connected locally can be helpful. This might be through regular dog-walks, visiting the same cafés, regularly attending a dementia support group, or even a short walk along a familiar route. These can help you to become recognized locally and to create a sense of belonging. If you are less able to get out and about, it is still possible to enjoy connections to others through visitors to your home. Sometimes, hearing the sounds of the neighbourhood, or the feeling of sunshine through the window, can be just as important. Neighbours popping by or having a chat over the garden fence or a conversation with a delivery person all have a part to play. Being able to see and hear the goings on can also help. Sitting in the front garden or near a window are small ways in which you might feel more connected to others.
- If you support a friend or family member living with dementia, or want to support people living with dementia in your neighbourhood, then you could help them to remain connected to other people and places nearby. Local relationships can provide important everyday support as well as assistance in times of need. Neighbours can be a useful point of call, from taking out rubbish to keeping an eye on someone. Being able to regularly visit local shops, such as the bakers or newsagents, can foster friendly local relationships. Attending local dementia groups can be an important way to stay connected, to create new routines and to meet new people. Local businesses can help customers feel welcome, providing assistance

with money, making purchases, or just by being patient or letting someone sit for a while on their premises.

- If you are involved in commissioning community support services for people affected by dementia then remember that many people living with dementia are already interacting with, and are a part of, neighbourhoods. Services should support people living with dementia to continue to do the things they are already doing, as well as encourage more people living with dementia to do more things. Start with what people can do, or would like to do more of, when designing or commissioning new services. Stay attuned to the importance of providing for the diversity of people impacted by dementia.
- If you are supporting people affected by dementia to be engaged in their neighbourhood in other ways, for instance as a city planner or policy officer, then a focus on how people actively 'do' neighbourhood, rather than on how people 'receive' them, could shift understanding beyond binary thinking about whether neighbourhoods are considered safe or unsafe, risky or risk-free, or even dementia-friendly or dementia-unfriendly. People living with dementia have experiential expertise about their neighbourhoods borne out of living with the condition. They should be part of any dialogue around how neighbourhoods can be improved. Sometimes, relatively simple changes can contribute to greater inclusivity for people living dementia, such as providing rest areas, seating at bus stops and accessible public toilets.
- If you are a dementia care researcher then remember to develop creative ways to enable people living with dementia to reveal what neighbourhoods mean to them. This includes thinking more creatively about how you do research with, rather than on or for, people living with dementia in neighbourhoods and exploring appropriate opportunities for involvement in all stages of the research process.



## Key Further Reading

Ward, R., Clark, A., & Philipson, L. (eds.). (2021). *Dementia and place: Practices, experiences and connections*. Bristol: Policy Press.

This edited collection includes several chapters that discuss findings from 'Neighbourhoods: Our People, Our Places' alongside contributions from researchers and people living with dementia exploring the relationship between place and dementia. The chapters authored by the 'Neighbourhoods: Our People, Our Places' team develop many of the themes presented in this chapter.

Clark, A., Campbell, S., Keady, J., Kuhlberg, A., Manji, K., Rummery, K., & Ward, R. (2020). Neighbourhoods as relational places for people living with dementia. *Social Science & Medicine*, 252. Available at: https://doi.org/10.1016/j.socscimed.2020.112927 (accessed 15 March 2023).

This paper argues for a relational understanding of neighbourhoods and includes further insight into how local social practices can support people living with dementia.

Campbell, S., Clark, A., Keady, J., Kullberg, A., Manji, K., Rummery, K., & Ward, R. (2019). Participatory social network map making with family carers of people living with dementia. *Methodological Innovations*, 12(1), 1–12.

This paper outlines one of three methods developed through 'Neighbourhoods: Our People, Our Places'. The participatory social network mapping method was used to understand how people's relationships and connections are understood in different contexts.

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