

# DEMENTIA + PLANNING:

## EXPANDING ACCESSIBILITY THROUGH DESIGN AND THE PLANNING PROCESS

### SUMMARY

Contrary to popular belief, over two thirds of Canadians with dementia live in the community as opposed to congregate living. This begs a question that has not been adequately explored in planning practice or academia: How can we as planners who deal with land-use, community design, and public consultation every day, understand and meet the needs of people with dementia (PWD), who are citizens just like everyone else? After examining existing work on the relationship between the built environment and PWD, I argue a dementia-specific approach to planning practice and research is needed in the Canadian context.

### RÉSUMÉ

Contrairement à une idée reçue, plus de deux tiers des Canadiens atteints de démence vivent au sein de la collectivité et non dans des habitations collectives. Cela nous amène à nous poser la question suivante, qui n'a pas suffisamment été étudiée dans la pratique et dans le monde universitaire de l'urbanisme : à titre d'urbaniste, nous gérons au quotidien l'aménagement du territoire et des collectivités, ainsi que des consultations publiques, que pouvons-nous faire pour comprendre et répondre aux besoins des personnes atteintes de démence, qui sont des citoyens comme les autres? Après avoir étudié les travaux déjà réalisés sur le rapport entre l'environnement bâti et les personnes atteintes de démence, j'avance qu'une approche de la pratique de l'urbanisme axée sur les personnes atteintes de démence est nécessaire au Canada.

Imagine you have lived in the same neighbourhood for the majority of your life. One day while out for a walk in your community, you realize that you have forgotten which street to turn at because most of the intersections in your community look the same. You get lost and don't remember how to get home. You feel anxious, frustrated, and disorientated. This is a common experience for Canadians with dementia. Dementia is an umbrella term used to describe a set of symptoms which affect memory, communication, ability to focus, reasoning, judgment, visual perception, and navigation. It is caused by over 100 conditions and diseases, the most common being Alzheimer's disease.<sup>1</sup> The World Health Organization calls dementia "the leading cause of dependency and disability among older persons in both high-income countries and low to middle income countries."<sup>2</sup> Globally, it is estimated that 47 million people currently live with dementia and this number will rise to 115.4 million by 2050.<sup>3</sup> In Canada, there were 747,000 people with dementia in 2011, and there will be 1.4 million by 2031.<sup>4</sup> At the local level, projections in Ontario suggest that suburban municipalities are expected to see the greatest increase in the number of people with dementia (PWD) from 2011-2032 of 250%-270%, compared to the provincial average of 170%.<sup>5</sup> The costs associated with care was \$33 billion in 2011 alone, and is projected to rise to \$293 billion by 2040 if nothing is done to change the current system.<sup>6</sup>

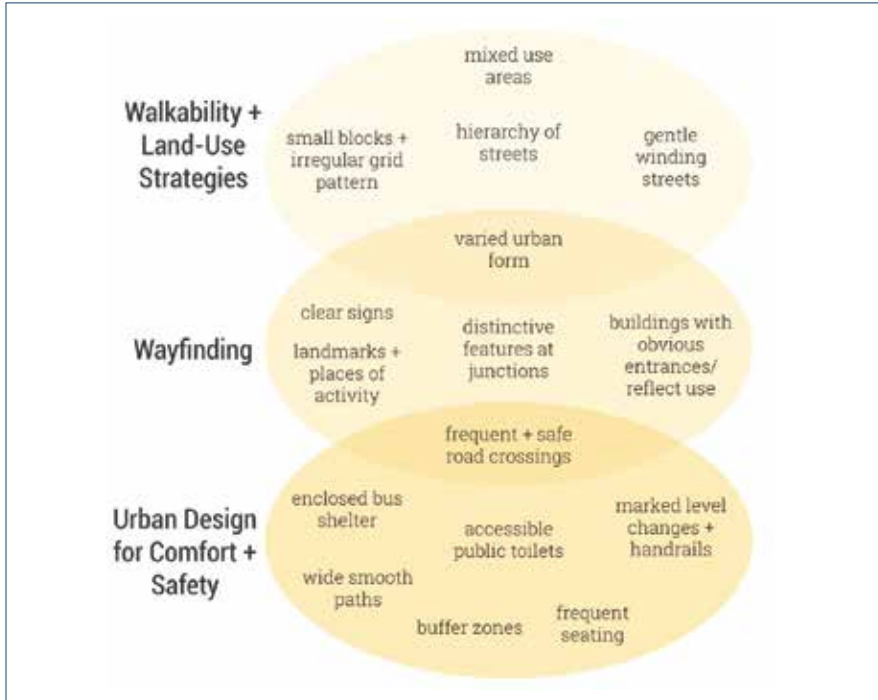
While many people believe that most PWD live in congregate living, Canadian estimates show that up to two thirds live at home in the community.<sup>7</sup> Combined with the overwhelming desire to age-in-place, this begs the question: what role does the neighbourhood play in the lives of PWD? Furthermore, how can we, as planners who deal with land-use, community design, and public consultation every day, understand and meet the needs of PWD, who are citizens just like everyone else? I believe that a dementia-specific approach to planning practice and research is needed. Such an

approach would encompass three interrelated processes: (1) building an evidence base for best practices in design; (2) altering the planning process to being accessible to PWD; and (3) changing the perceptions of PWD by planners and city builders.

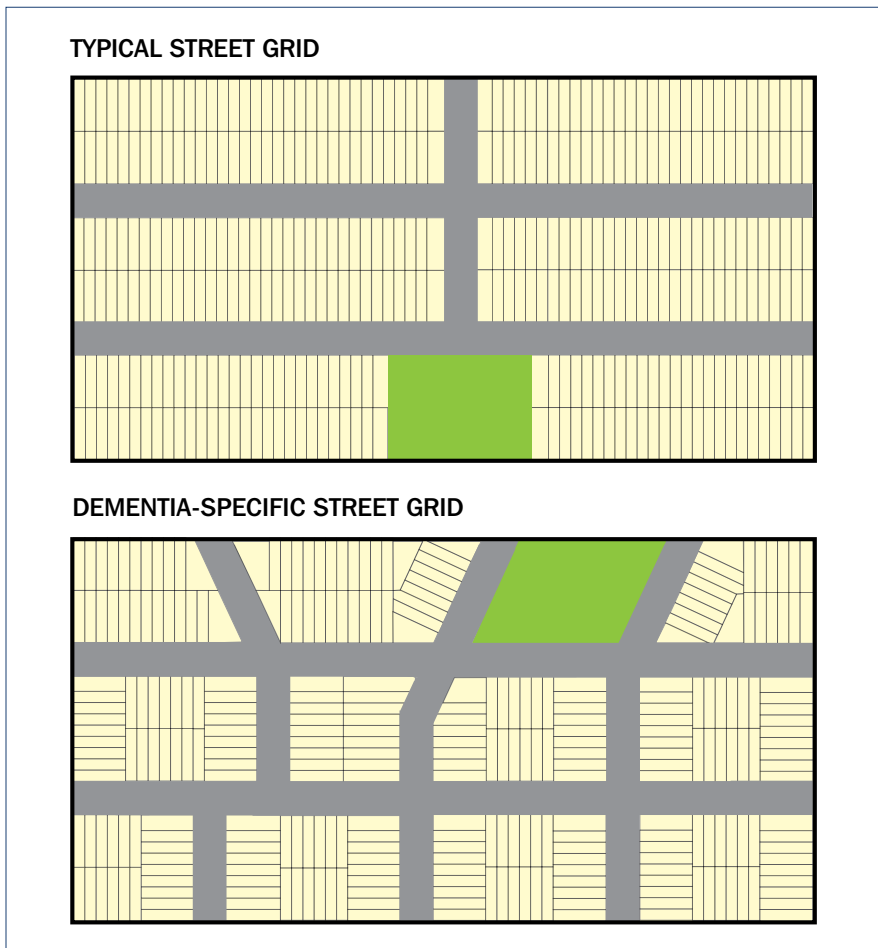
Research suggests that for PWD, being enabled to use their neighbourhood provides a sense of freedom and autonomy, dignity and a sense of worth, physical exercise, psychological wellbeing, and social interaction.<sup>8</sup> As we age, our conceptual and physical access to the world shrinks. One study of the mobility of older adults in Israel demonstrated that, on average, an older adult without dementia travelled approximately 1.5km from their home, while an older adult with mild dementia only travelled 400m. Surprisingly, the research on the relationship between the built environment and PWD is scarce, and so far, has only been based in Europe.<sup>9</sup> Policy approaches like age-friendly cities, dementia-friendly cities, and universal design, while good starting points, are insufficient in understanding how PWD experience their cities, and the role of land-use planning and design.<sup>10</sup> We have to find out what may enable or disable PWD in their neighbourhoods in order to build a context-specific evidence base for policy recommendations. Just as we know those in wheelchairs require ramps to access buildings, we have to find out what are the *cognitive ramps* for PWD in our built and social environments.<sup>11</sup>

While the needs of PWD and older adults often intersect, their needs are not identical, indicating the necessity for dementia-specific work. Seminal research from the UK offers 17 recommendations for land-use and urban design, which fall within three overlapping groups: urban design for comfort and safety, walkability and land-use strategies, and wayfinding. Wayfinding in particular is not typically discussed in research on older adults<sup>12</sup> (Figure 1).

**FIGURE 1 – SUMMARY OF DEMENTIA-SPECIFIC DESIGN RECOMMENDATIONS**



**FIGURE 2 – TYPICAL VS. DEMENTIA-SPECIFIC STREET GRID**



The issue of wayfinding is important. The status quo method of building a new suburb is to use one style of house with a few small variations with identical crossings and features throughout the development. Even if you are able-bodied, you may have become lost in a suburb before, as everything tends to look similar. As Lynch discussed several decades ago in *The Image of the City*, human beings have navigated using landmarks since the beginning of time, and people today use comparable strategies. PWD rely on landmarks to situate themselves, and those in a monolithic suburb will probably be at a greater disadvantage than someone living in a neighbourhood with recognizable differences. Based on the study in the UK, municipalities could encourage the following to improve the built environment for PWD:

- **A short, irregular grid pattern of streets** to create identifiable intersections and allow residents to visualize their travel path, and provide multiple routes for wayfinding (**Figure 2**);
- **Streets with ample space for pedestrians**, with no drastic changes in colour (which can be perceived by PWD as holes in the sidewalk), and with wide buffer zones between pedestrian paths, cycling paths and roads;
- **Variation in architectural styles within the same development, mixed land-use, designs incorporating diverse styles of street furniture, public art, and vegetation** in order to vary the landscape and provide unique landmarks for improved navigation;
- **Improved wayfinding signage** that uses textual information ('5 minute walk to the library') and realistic photos (instead of icons, which can create confusion) (**Figure 3**);
- **Development of memorable landscape features, open public squares, and community facilities** that promote social interaction and foster a sense of belonging.<sup>14</sup>

All 17 of these recommendations when applied to greenfield development were found to be economically feasible, achievable within current Ontario planning frameworks and each supported by at least one peer reviewed study.<sup>15</sup>

In addition to the need to build evidence for what those *cognitive ramps* may look like,

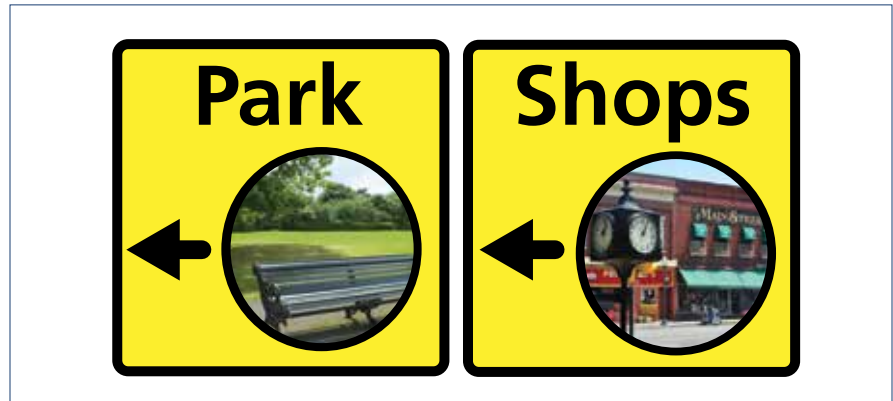
there is a strong potential role for planning to enable PWD to exert their power as citizens through the planning process, and to combat the intense stigma that surrounds a diagnosis of dementia. Activists suggest that PWD be considered as people with a disability, with rights to be accommodated.<sup>16</sup> They problematize the negative stigma and demeaning language PWD face, advocate research with PWD rather than only their caregivers or healthcare providers, and reject the idea of 'prescribed disengagement'.<sup>17</sup> Invitation of PWD into the planning process in a meaningful accessible way has the potential to serve as a disruptor to these overarching narratives, by enabling PWD to assert their right to shape their city as a citizen.

There has been a recommendation to the United States government from scholars, to expand the studying of PWD from health and social care to that of urban planning and community development.<sup>18</sup> It is pertinent that all levels of government consider the role of the neighbourhood when developing policy strategies for PWD. While the built form interventions mentioned in this article are a good starting point, it is important to note that they are based on a singular study in the UK. There is a need for research in the Canadian context.

As planning professionals and scholars, we have to look beyond accessibility as solely based on physical or sensory impairments. We have to think about how people with cognitive impairments or intellectual disabilities experience the places they live in, by asking them personally. We have to explore not only how to do this through physical design, but also how to adapt our consultation practices to their preferences and needs. Researchers and planners on the ground need to work together with PWD to help determine best practices in the years to come.

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FIGURE 3 – DEMENTIA-SPECIFIC WAYFINDING SIGNAGE



#### (Endnotes)

- <sup>1</sup> About 60-80% of all dementia is caused by Alzheimer's disease. Alzheimer's Association. (2016). *What is dementia?* Retrieved from: <http://www.alz.org/what-is-dementia.asp>
- <sup>2</sup> World Health Organization. (2012). *Dementia – A Public Health Priority*. Retrieved from: [http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf) p.8
- <sup>3</sup> World Health Organization. (2012). *Dementia – A Public Health Priority*. Retrieved from: [http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf) p.8
- <sup>4</sup> Alzheimer Society of Canada. (2012). *Rising Tide: A new way of looking at the impact of dementia in Canada*.
- <sup>5</sup> Hopkins, R. W. (2010). *Dementia projections for the counties, regional municipalities, and census divisions of Ontario*. Kingston, ON: PCCC Mental Health Services. Retrieved from: <http://www.alzheimertoronto.org/pdf/brochures/Hopkins2010.pdf>
- <sup>6</sup> Alzheimer's Society. (2016). *Dementia 2014 Report Statistics*. Retrieved from: <https://www.alzheimers.org.uk/statistics>
- <sup>7</sup> Alzheimer's Society. (2016). *Dementia 2014 Report Statistics*. Retrieved from: <https://www.alzheimers.org.uk/statistics>
- <sup>8</sup> Burton, E. & Mitchell, L. (2006). *Inclusive urban design: Streets for life*. Oxford, UK: Elsevier Ltd. p.39-41
- <sup>9</sup> Keady, J., Campbell, S., Barnes, H., Ward, R., Li, X., Swarbrick, C., Burrow, S. & Elvish, R. (2012). Neighbourhoods and dementia in the health and social care context: a realist review of the literature and implications for UK policy development. *Reviews in Clinical Gerontology*, 22 (02), 150-163.
- <sup>10</sup> Biglieri, S. (2015). *Building a dementia-friendly neighbourhood: An examination of the economic costs of implementing 'dementia-friendly' urban design and land use strategies in Whitby, Ontario* (Major Research Paper). Ryerson University, Toronto, ON.
- <sup>11</sup> The term *cognitive ramps* is a metaphor from Dementia Alliance International member Peter Mittler, from: Graham, J. (2017, March 10). Don't write us off: People with dementia press for more rights – and respect. *StatNews*. Retrieved from: <https://www.statnews.com/2017/03/10/dementia-human-rights>
- <sup>12</sup> Burton, E. & Mitchell, L. (2006). *Inclusive urban design: Streets for life*. Oxford, UK: Elsevier Ltd.
- <sup>13</sup> Biglieri, S. (2016). *Implementing dementia-friendly land use policy: An evaluation of current literature and economic implications for greenfield development in suburban Canada*. Paper presented at the 56th Annual Association of Collegiate Schools of Planning Conference, Portland, Oregon.
- <sup>14</sup> Biglieri, S. & Dean, J. (2017). Aging in suburbia, in M. Moos & R. Walter-Joseph (Eds.), *Still detached and subdivided? Suburban ways of living in 21st century North America*. Berlin, DE: JOVIS Verlag.
- <sup>15</sup> Biglieri, S. (2015). *Building a dementia-friendly neighbourhood: An examination of the economic costs of implementing 'dementia-friendly' urban design and land use strategies in Whitby, Ontario* (Major Research Paper). Ryerson University, Toronto, ON.
- <sup>16</sup> Lin, S. Y., & Lewis, F. M. (2015). Dementia friendly, dementia capable, and dementia positive: concepts to prepare for the future. *The Gerontologist*, 55(2), 237-244.
- <sup>17</sup> A term coined by Swaffer (2014) to refer to the tendency of doctors when giving a diagnosis of dementia to encourage patients to 'get their lives in order' and begin retreating from their lives. Swaffer (2014)
- <sup>18</sup> Lin, S. Y., & Lewis, F. M. (2015). Dementia friendly, dementia capable, and dementia positive: concepts to prepare for the future. *The Gerontologist*, 55(2), 237-244. ■