

Expert essay

How to maintain community participation while living with dementia?

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Out-of-home participation, or community participation, is an important part of everyday life for many people, including those living with dementia in their community. However, it is also a challenge due to cognitive impairments. People living with dementia and their families report difficulties related to finding one's way, getting lost, being stigmatised and embarrassed, and getting injured. Community participation is understood here as the engagement in meaningful activities performed in places located outside the home; it is contextualised, situated, and embedded in places visited by people[1]. Thus, community participation is experienced as a person-environment relationship while engaging in meaningful activities[1].

Older adults including those living with dementia value community participation for various reasons, such as increased opportunities for autonomy and freedom, physical activity, contact with nature, meaningful relationships, and social interactions[2]. Community participation has been shown to prevent depression, reduce anxiety, as well as foster one's identity and sense of self, and to offer diverse opportunities for social contact. Furthermore, being able to engage in community participation increases connectedness, belonging, and awareness of the environment for people living with dementia[1,2].

Going "out and about" becomes a challenge for many people living with dementia and their families as the disease progresses. Space outside the home is often seen as fraught with risks and considered to be hazardous for people living with dementia, with respect to the complexity of navigating the outside world[3], for instance due to traffic, crowding, noise, and unpredictable road works. People living with dementia and their families report difficulties related to finding one's way and getting lost. Little by little, people living with dementia disengage from social group activities like being a member of associations or clubs and going to social gatherings, exhibitions, or concerts. They also face driving cessation, which increases the feeling of a "shrinking world"[4]. However, results from recent studies conducted in Canada, Sweden, Switzerland, and the United

Kingdom have shown that people living with dementia do not experience a global and linear decrease in their community participation, but rather a shift from visiting social and cultural places to places used for medical and self-care[5,6]. Although the number of places visited while engaging in community participation diminishes, the places that are maintained, such as the neighbourhood, may become particularly meaningful for people living with dementia and their families[1].

Space located outside the home is an unlimited and unspecified environment. For it to become a life-space that people may navigate, people need to perform meaningful activities of their everyday life and experience a relationship with the environment where they situate their life stories[7]. As activities are performed in a specific place, this place becomes a part of the individual's life story and life world, linked to one's identity. The individual is seen as embedded in places, in constant relation with their environment through the performed activity[8], creating an "enacted togetherness" that situates activities into meaningful places. By maintaining and engaging in community participation, people living with dementia build a sense of familiarity and belonging toward their life-space and meaningful places, like the local grocery shop, park, or café.

An "enacted togetherness" supports the experience of familiarity that individuals build over time by repeatedly visiting places and performing activities that feel familiar. Losing this sense of familiarity may lead to insecurities and disorientation, fear of going outside, and disengagement from community participation. Landmarks emerge from the experience of community participation and their saliency may support navigating the life-space[9]. According to a relational and transactional perspective, familiar and lived places support the experience of maintaining one's identity and include an affective (place attachment) and cognitive (identity) link to that place. Familiarity is situated, embedded, and enacted in the experience of embodied places to which people living with dementia travel and visit[10]. People living with dementia maintained a sense of self through the

experience of familiarity in the places they visited. They also shared meaning with significant others that connected them to the places they visited.

By connecting with significant and important places while navigating the life-space, people living with dementia create “territories” in which they feel safe, cannot get lost, and thus may take risks in. These territories are formed from networks of functional, symbolic, relevant, relational, habitual, and familiar places that transcend geography to highlight the interconnectedness of places, activities, and people[10]. These territories are built progressively through repeated occurrences of community participation in meaningful activities and places.

Furthermore, people take objects with them when going “out and about.” These may include, for example, a purse, keys, a cane, a bottle of water, a handbag, or an umbrella. At first glance, taking objects when leaving the house may not seem to be of interest. However, these objects take on

a particular meaning in a relational and transactional perspective on community participation. People living with dementia take these familiar objects to stay connected to their home and to feel safe and secure while participating in their community. The objects embody the idea of home as being secure and familiar. The concept of embodiment shows that objects are also connected to one’s identity and sense of self, thus refuting a mind-body dualism[11], and instead creating an extension of oneself through everyday objects.

Taken together, this recent body of research underscores the importance for health professionals to support and maintain community participation through repeated visits to meaningful places where people living with dementia may succeed in performing activities, to increase familiarity of their maintained territories. Moreover, there is a need for greater awareness of the importance of familiar objects and landmarks to facilitate community participation among people living with dementia.

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**Alzheimer's Disease
International**

The global voice on dementia

World Alzheimer Report 2022

Life after diagnosis:
Navigating treatment, care and support

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Alex Kornhuber is a Global Atlantic Fellow for Equity in Brain Health whose
work has notably focused on portraying older people in Peru.

The opinions expressed in the essays included in this report do not neces-
sarily reflect the positions of ADI or McGill.

Published by Alzheimer's Disease International.

September 2022

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Suggested citation:

Gauthier S, Webster C, Servaes S, Morais JA, Rosa-Neto P. 2022. World
Alzheimer Report 2022: *Life after diagnosis: Navigating treatment, care
and support*. London, England: Alzheimer's Disease International.

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