



How to engage and support people living with dementia in Dementia Friendly Communities

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The genuine engagement of people living with dementia is integral to creating authentic Dementia Friendly Communities (DFCs). Alzheimer's Disease International has defined a DFC as: "a place or culture in which people with dementia and their carers are empowered, supported and included in society, understand their rights, and recognise their full potential", (ADI, 2016). An example of this is Memory Cafes, which aim to provide an open, accessible and supportive space for family carers and people

living with dementia (ADI, 2016).

DFCs hold the assumption that communities are currently not friendly or inclusive of people living with dementia. DFCs seek to create a supportive and welcoming environment shaped by and with people living with dementia.

DFCs are expanding globally (Alzheimer's Disease International [ADI], 2016). Initiatives must actively engage and accommodate people living with dementia through inclusive, effective practices. The

World Health Organisation's (WHO) global action plan response to dementia has seven key action areas. Action area 2 prioritises dementia awareness and friendliness, aiming for 100% of the 194 WHO member states to have a public dementia awareness campaign and at least one dementia-friendly initiative by 2025 (World Health Organisation, 2017). In 2021, 75% of member states had national dementia plans, and 50% had at least one dementia-friendly initiative (World Health Organisation, 2021).

A key feature of DFCs is the inclusion of people living with dementia, yet globally and nationally this is still limited. Buckner et al. (2018) in the UK found that only one-fifth of DFC initiatives involved people living with dementia. Closer to home in Australia, we found that the involvement of people living with dementia in initiatives was limited or non-existent (Grogan, 2022). With one committee having a person living with dementia as chair, and another committee without people living with dementia in attendance (Grogan et al., 2024). These findings show how wider systemic and societal barriers can impact the local creation of DFCs.

The central question to consider is: is it dementia-friendly if people living with dementia are omitted? Tangible changes in practice and process can ensure the authentic inclusion of people living with dementia and their family carers. Below are some ways to help achieve active and valuable engagement within DFCs.

Five tips to start a DFC



Invitation

- Actively invite people living with dementia and family carers in initiatives. For example, put up flyers or advertise in the local newspaper, community or church noticeboard, call local respite centres and share with them to invite family carers and people living with dementia, or attend a local memory café and invite people. The key is to go where they might be, actively engage, and demonstrate how you value their opinions and time by giving your own. Most importantly, people living with dementia should be asked how they would like to be involved.

Create a subgroup

- People living with dementia often prefer and are more comfortable in smaller groups, so creating a smaller group that meets informally, such as once a month, can act as a bridge to the larger

community. The smaller group can build trust, rapport and supportive relationships, which can then help guide the larger DFC committee's actions and priorities.

- Creating a dementia café (informal regular catch-up group) can be a practical way of meeting people living with dementia and providing an environment to build social support and community connection.



Leadership and sharing of power

- Collectively make decisions *with* people living with dementia instead of *for* them. For example, call people before the meeting to ask for their input on the agenda topics and/or any feedback from prior meetings.
- Support people living with dementia and family carers in advocacy and leadership positions. Be flexible in responding to how involved people living with dementia wish to be. Support someone who wants to be more engaged and active in initiatives. See what would be needed to make it happen. For example, someone can assist with minutes and help prompt meetings.

Facilitation and timing of meetings

- Call and remind people about a meeting.
- The facilitator needs to be empathetic, clear and communicate effectively.
- Limit the number of agenda items and allow time before the meeting for input in various ways, such as phone, email and text.
- Allow for more time to slow things down to include people living with dementia authentically.

Location

- Select an accessible location that is easy to get to and has appropriate surrounding and internal signage. Somewhere that fits into the DFC design principles would be ideal.
- A consistent location allows for a routine to be established for families and people living with dementia.
- Facilitate transport for people living with dementia to attend meetings.

People living with dementia have demonstrated their interest and ability to participate in DFCs and associated research.



Flexible approaches are needed to facilitate the active involvement of people living with dementia (Grogan et al., 2024). By implementing these critical steps in creating DFCs, the authentic engagement of people living with dementia can be supported to value their voices, making a tangible difference for them and the DFC movement.

Author

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