

TITLE: Co-designing with community to create a dementia friendly environment in Forest Hill

BACKGROUND

Dementia affects more than 332,000 Australians, along with their family and friends, and is the second leading cause of death in Australia with no cure. Victoria had approximately 105,000 people living with dementia in 2017 (Dementia Australia 2017). Four of the seven eastern metropolitan region local government areas were ranked within the top 10 in regards to prevalence of dementia in 2016: Monash (3), Whitehorse (4), Boroondara (5), and Manningham (10). (NATSEM, 2016)

The National Framework for Action on Dementia 2015-2019 (Commonwealth of Australia, 2015) identifies the need for collaborative approaches to dementia-friendly communities in Australia in order to build awareness, acceptance and understanding of dementia in the community:

The development of dementia friendly services and approaches may help to promote awareness and create communities which are more inclusive and accepting of people with dementia. For this to occur, the communities, including local businesses, health care professionals and other service providers should improve their understanding and awareness of dementia. The provision of amenities, goods and services in a user-friendly manner that meets the needs (including co-vulnerabilities) of people with dementia and their carers may help to facilitate inclusion. (p.8)

Victoria's Dementia Action Plan 2014-18 (Victorian Government, 2013) had seven priority action areas to improve responsiveness of the health system and wider community for people with dementia, their families and carers. One of these action areas is to promote dementia friendliness in age friendly communities:

A dementia-friendly society has been defined as a cohesive system of support that recognises the experiences of a person with dementia, and supports them to remain engaged in everyday life in a meaningful way (Davis et al. 2009)

According to Dementia Australia, a dementia friendly community is "a place where people living with dementia are supported to live a high quality of life with meaning, purpose and value" (Dementia Australia 2019, p. 5).

Most people living with dementia are living at home in the community, but risk becoming isolated as their dementia impacts on them and their carer's.

In their 2014 survey with people living with dementia, Dementia Australia found that people living with dementia and their carer's are more lonely than others and wanted increased awareness about dementia, access to social and employment opportunities, access to services, access to transport and better physical environments for their needs (Dementia Australia 2019, p.4). In addition, providing support to a person living with dementia can have a substantial impact on the wellbeing of the carer. The demands of caring can put carer's at risk of depression, stress and anxiety, as well as social isolation and poor health generally. (Dementia Australia 2015). Carer's also experience the stigma of dementia feeling "set apart"

from others and feeling isolated as friends and family lack understanding about dementia (Dementia Australia 2017).

Increased awareness and understanding and more dementia friendly environments can provide more welcoming and inclusive places for people living with dementia and their care'rs to continue participating in community life.

A key aspect of a dementia friendly community approach is to involve people living with dementia and their carer's in the design of dementia friendly actions for local communities, under the motto of "nothing about us, without us". This ensures that outcomes are informed by lived experience.

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PARTNERS

Eight community members – 7 carers and 1 person living with dementia, and 8 organisational representatives that work with older people living with dementia came together to form a working group and codesign actions

- Inner East Primary Care Partnership (Lead)
- Whitehorse Council
- Carrington Health
- Care 3
- Uniting (2)
- Villa Maria Catholic Homes
- Home Instead Senior Care

METHOD

This initiative aimed to establish a pilot model of working with community members and organisational stakeholders to plan and implement actions in Forest Hill to become more dementia friendly, targeting people living with dementia and their carers/family/friends living in or close to the suburb of Forest Hill.

Forest Hill is a suburb located in the Eastern suburbs of Melbourne, and part of the Whitehorse local government area. Forest Hill has approximately 1,380 people currently living with dementia and a high proportion of older residents with 15.5% aged 70 years and over (2016 Census). The working group agreed to focus on businesses and retailers in Forest Hill Chase, a mid-size, undercover, shopping centre in Forest Hill.

The key components of co-designing solutions for a more dementia friendly community are:

- A strong partnership between organisations and community
- Leadership from key organisations that can support the partnership
- A good understanding and application of co-design principles and practices for all members of the partnership
- Knowing what dementia friendly communities approaches are
- Active involvement of people with lived experience
- A willingness to listen and share with all members of the partnership
- Balancing power in the group and creating space for an equal voice for all group members
- Use of external expertise when required, such as a facilitator or graphic designer

This work has developed over 3 years:

In August 2016 a group of community service organisation representatives agreed to work together to improve the wellbeing and quality of life of people living within dementia in Forest Hill. This group focused on community consultation through surveys and interviews to find out what is important in a dementia friendly community to guide actions for the working group. A total of 332 online and written surveys were completed, and 60 carers, people living with dementia and care support workers were consulted through focus groups and interviews. The consultation also provided an opportunity to promote the work to potential community members to join the group.

In March 2018 the group expanded to include recruited community members living with dementia and their carers. Currently, there are six service providers and seven community members in the group. Community members were recruited via the consultation process and through connections of organisational representatives.

At the same time, a Community Engagement Grant application to Dementia Australia was submitted with support from the group. The application was successful, providing \$15,000 from Dementia Australia to support the work.

Adopting the dementia friendly community philosophy of involving people with lived experience to design actions, it was important to ensure the working group understood co-design well. IEPCP spent time with organisational group members prior to the inclusion of community members in building their understanding of co-design. Five members of the group, including 3 community members, also participated in a partner forum about co-design organized by the IEPCP and facilitated by the Australian Centre for Social Innovation (TACSI). The forum introduced members to co-design principles and practices such as equalizing power, understanding roles within the group, taking time

to build relationships and providing the appropriate supports for community members to participate, such as transport.

Co-design principles were applied to the Forest Hill DFC group in the following ways:

- Engagement of an external facilitator for the first few meetings to supporting building trust and rapport, establish ways we work together, equalise power, and ensure all voices were heard.
- A guide to how community members could be supported to participate was agreed to and community members are provided with some reimbursement of their time through shopping vouchers; in addition, respite and transport were offered when needed.
- Respecting all contributions and providing opportunity for all members to have a voice.

In July 2018, the group discussed and came to a consensus that their aim is to *“make Forest Hill a place where people living with dementia, and their family and friends, feel supported to participate in their community”*.

The group consolidated 30 project ideas, taken from the consultation and group members’ interests, into six action areas. Criteria were developed to assess these and consensus was achieved on two priority actions:

- help businesses to have an understanding about people with dementia.
- assist people with dementia and their carers to know where to get help

With funding support from Villa Maria Catholic Homes, the group agreed to focus specifically on working with a café at Forest Hill Chase to become more dementia friendly as an “anytime” option for people living with dementia and their carers.

In 2019, with good relationships, trust and rapport established between group members, a more traditional style of meeting has been implemented with the agenda and minutes recording progress on actions for the “anytime” café and tasks to be undertaken before the next meeting.

Group members participate in how actions will be progressed, what resources are needed and how these will look. They also share ideas and dementia friendly resources. All members of the group have contributed to actions, such as scouting potential cafes to work with for suitability, reviewing training options, developing physical environment checklists, and providing meeting spaces.

Challenges for the group have been the meaningful engagement of people living with dementia. It has been relatively easy to recruit carers to the group, but not as easy to recruit people living with dementia. Other ways of future engagement need to be considered. Another challenge has been setting the pace of work. Enough time is needed to genuinely co-design actions, while spending too much time can be a source of frustration for group members.

The project relies on the successful partnership of all the organisation and community representatives involved, ensuring a genuine co-design approach and providing the resources required to develop and implement actions.

The group will ensure the resources and knowledge developed throughout the project are shared in the region and nationally through the Dementia Australia Dementia Friendly Hub.

OUTCOMES

In August 2019 group members were surveyed to get their feedback about the codesign process used. 14 surveys were received, 12 from current members and 2 from recent past members. 7 surveys were completed by community members and 7 by organisational representatives. The survey identified some areas for improvement, including improving orientation for new group members. The survey also identified areas we are doing well, with all members responding that they always or mostly:

- feel valued and able to contribute to our aim;
- feel they have an equal say
- feel they could be honest and share their ideas and opinions.
- And feel included in the decision making.

In addition, success factors for the work so far include:

- Establishment of a cohesive and committed partnership between community members and organisations
- Using the principles and practices of co-design to develop and implement actions
- Development of a common goal towards a more dementia friendly community in Forest Hill
- Enthusiasm to work with businesses and retailers at Forest Hill Chase to support them to become more dementia friendly

Other outcomes have been:

Friendship

Positive peer support: Members of the working group, many of whom are current or recent carers of someone living with dementia (including those from organisations), are supporting and encouraging each other in a variety of ways that were not intended or expected. For example, providing IT advice and help to each other, attending a family funeral of one of the members, and encouraging each other to take time out to rest. Community members have shared their contact details with each other, and some are in contact socially outside of the working group. Organisational members are able to provide appropriate personal support and links to services when there is a need.

Capacity building

Building the capacity of working group members to understand what co-design is and how it can be implemented has been an important element of this work. Working group members, including organisation representatives, have learned about co-design in practice and built their skills which can be used in other settings.

Resource development

During the work, the group has developed a number of resources and also adapted and learned from existing resources. For example, the group has a web page on the IEPCP website, it also has an internal webpage for sharing resources with each other. Flyers, action plans, surveys, interview schedules, promotional materials, short reports, and presentations have all been developed and used in the course of the work. The group has developed branding and will produce collateral such as brochures, community promotional flyers, stickers and posters to use with businesses. The group will ensure the resources and knowledge developed throughout the project are made available to the wider community. Some of this will also be shared on the Dementia Australia Dementia Friendly

Hub. We also should not underestimate the connections group members have to others and their capacity to share the dementia friendly philosophy in their own circles of family, friends and colleagues. The more that dementia friendly community ideas, resources and knowledge are shared, the greater the impact will be on the quality of life of people living with dementia and their carers.

Equitable partnerships

When organisations are co-designing solutions with people with lived experience, ensuring a balance of power and equal voice for all participants are keys to success. This includes:

- Taking time to build trust and rapport with community members and to establish how you will work together;
- Not underestimating the skills and value of community members;
- Reimbursing community members for their participation to recognise the resource they provide;
- Using a skilled, external facilitator at key points, who has a good understanding of co-design and the ability to quickly build rapport and positively engage the group;
- Using appropriate communication methods for all, such as large front print and plain English for documents;
- Having concrete actions to focus on but keeping sight of the bigger picture at all times.

Meaningful engagement of those with lived experience

Meaningfully engaging people living with dementia can be a challenge for dementia friendly community work. While carers are keen to participate, it has been difficult to recruit people living with dementia to the group. Other ways of involving people living with dementia in this work need to be considered. This could include attending dementia groups and taking ideas to them for discussion, recruiting individuals for consultation from time to time, and walking with them to better understand their experience of their local area.

This initiative is currently ongoing with support from 6 organisations and 7 community members. Group members are passionate about changing the community to improve the health and wellbeing of people living with dementia. The current level of commitment from community members may not be sustainable. The group may need to transition to an advisory role that meets less frequently and provides timely advice rather than the more detailed and time consuming co-design approach. This will require coordination which may need to be transferred in the future from the IEPCP to another organisation.

While this initiative is a great example of a strong partnership with organisations and community members, the IEPCP played an integral role in initiating and then coordinating the partnership throughout. As a PCP we can provide an objective overview as we are not a service provider or aligned with a particular issue. We also bring a focus on primary prevention and the benefits of aiming for structural and systems change for longer term health and wellbeing outcomes. We are able to offer specific knowledge and capacity building skills to the partnership, such as co-design and community engagement principles and processes, and have connections and contacts to engage external consultants when required.