

FOREST HILL

DEMENTIA FRIENDLY COMMUNITY



Consultation Summary April 2018

The Forest Hill Dementia Friendly Communities Project consists of a number of phases with the first being a consultation phase to guide the development of the overall project. A key component of the consultation phase includes talking to people with dementia and their families and carers, about what is important to them - “*nothing about us without us*” - as well as the broader local community, service providers and businesses.

Methodology

Consultation was undertaken from March 2017 to March 2018 via community surveys and informal interviews and group discussions with people living with dementia, their families and carers.

The Forest Hill Dementia Friendly Communities Project Working Group adapted a survey and interview questions from the Alzheimer’s Australia *Local Government DFC Toolkit* (Alzheimer’s Australia, 2015) and the United Kingdom Department of Health *Dementia 2020 Citizens’ Engagement Programme Toolkit for engaging people with dementia and carers* (Department of Health United Kingdom, 2016). A group of people living with dementia and their carers were consulted about the survey questions and promotional material.

The community survey was prepared in hard and electronic versions in easy English, Greek, Italian and simplified Chinese in large font format (based on Manningham general community survey) and distributed through working group contacts to senior’s groups, community members, shopping centres and promoted through a flyer and in newsletters. The working group also contacted people living with dementia and their carers, to conduct individual interviews and groups discussions.

The community survey was confidential, anonymous and voluntary and the working group developed key messages in a variety of formats to promote the consultation. This included a flyer, letters for senior’s groups, and an information sheet for organisations. These messages were also adapted as required to suit the specific needs of the target audiences.

A total of 332 surveys were collected and more than 60 carers, people living with dementia and paid support workers were interviewed or involved in informal group discussions. For a full list of those who participated in the consultation process please refer to Appendix A: Consultation Participants on page 7.

The overall findings of the consultation phase will be used to guide future actions to create a dementia friendly community in Forest Hill.

Results

Community Survey

General community members including people with dementia and their carers, such as local residents, students, business owners, workers, sporting and community group members and visitors who are active in Forest Hill were encouraged to complete the survey. A total number of 332 community surveys were completed, 311 were hard copy and 21 were done online.

In regards to gender 114 (34.34%) males completed the survey and 214 (64.46%) females, 3 people (0.9%) failed to respond to the question, and 1 person (0.3%) chose to self-describe, however didn't complete their answer.

The age of the respondents were 18-25yrs (3.02%), 26-40yrs (4.53%), 41-55yrs (9.37%), 56-70yrs (17.52%), 71-84yrs (52.56%), 85+ (13%). The higher number of older people completing the survey generally reflects where the majority of hard copy surveys were distributed, such as local senior citizen clubs.

Most spoke English at home 171 (51.66%), with 91 (27.49%) speaking Greek and 27 (8.15%) of respondents listing other, which included a variety of languages such as Tagalong (Filipino), Croatian, Cantonese and Mandarin.

A total number of 324 respondents identified which suburb they lived in, with the top 5 responses being Blackburn 28 (8.64%), Forest Hill 32 (9.87%), Nunawading 23 (7.09%), Box Hill 22 (6.79%) and Burwood East 18 (5.55%) which are all located within the City of Whitehorse. The highest responses for people residing outside the City of Whitehorse was Doncaster 14 (4.32%) and Doncaster East 10 (3.08%) which are suburbs located within the City of Manningham. A total of 215 (66.35%) lived within the City of Whitehorse.

Respondents were asked to identify their connection with the suburb of Forest Hill, being the primary location of the dementia friendly communities project. The majority of respondents 123 (42.7%) were visitors to Forest Hill with the most common reasons being to shop, attend church or meet with family and/or friends. The second highest response was from community members/residents 112 (38.88%), followed by those who worked in Forest Hill 32 (11.11%).

People were also asked questions specifically about dementia which included rating their level of knowledge about dementia. The highest number of respondents 162 (51.42%) stated that they were somewhat knowledgeable, however just under a quarter or 23.8% said they were not too knowledgeable or not all knowledgeable, 34.72% said they knew how to support people with dementia, while 42.12% said they didn't and 76.84% said that they would like to know how to better support people living with dementia.

Survey respondents believe that the 3 most effective ways of helping people to understand more about dementia are;

- Information on TV and radio (53.53%);
- Education in schools (40.06%) and
- Community events and presentations (38.46%).

Promoting research findings ranked slightly less than community events and presentations (36.21%) and other suggestions included; visiting senior's clubs of all nationalities, talking to social groups, education within the local community, council and, aged care facilities and retirement villages for staff and residents.

Respondents identified that the 3 most important features of a dementia friendly community are; support to stay at home 186 (61.18%), having social activities for people with dementia 168 (55.26%) and community awareness of dementia 166 (54.60%). The physical environment and clear signage rated 34.53% and 32.23% respectively. Other suggestions included; communication, information of where to get help, family members being aware of how to provide appropriate care and acceptance.

Over half the people surveyed 54.01% strongly agree or agree that people with dementia have something to offer their communities and 52.73% agreed that Forest Hill is a place where someone with dementia could live a quality life.

Interviews and Group Discussions: carers and support workers

A total number of 19 carers and approximately 25 paid support workers either participated in individual interviews or group discussions. All rated their knowledge about dementia as good to very good.

The most challenging aspects of caring for a person with dementia are:

- The need for patience e.g. repetition of questions from the person with dementia and their lack of insight, unpredictability and changes in behaviour;
- Emotional stress and social isolation;
- Frustration;
- Loss of relationship, the person with dementia doesn't know who you are;
- Being "on your toes" and having to look out for them at all times, being on call 24/7, emotionally and physically tiring;
- Keeping the balance between the dignity of the person with dementia and their safety;
- The feeling that family and/or friends don't understand the carers role or dementia.

All of the carers said that their lives are impacted dramatically as carers, such as:

- Being housebound;
- Their inability to socialise, lost contact with friends and only sometimes talk on the phone which is also difficult;
- Stopped working, studying and hobbies;
- Spend a lot of time organising services and assessments or attending appointments;
- Don't go on holidays as the benefits don't outweigh the trouble

The things that carers believe would assist in helping to care for someone with dementia are:

- Try to keep the person with dementia focused on the routine and what comes next, what they need;
- More accessible parking options and buildings e.g. handrails and ramps and accessible toilets;
- Age-friendly seating and less noise in cafes and shopping centres and quick service;
- More education and awareness of the community about dementia, including schools, workplaces and local businesses;
- More empathy, compassion and patience within the local community, particularly local businesses.
- Supportive family, carers and friends.

However, they also identified what makes it difficult to go out with a person with dementia:

- Finding a suitable place to go;
- Incontinence issues;
- Lack of seating at shopping centres;

- Accessibility, not always easy to get from the car to the lift, not enough disabled carparks, trip hazards such as gutters in the carpark, escalators are difficult to negotiate, travelators and lifts are better.
- Change of management/business owners and the types of food served.

The carers also provided responses on what they believe are important features to making a dementia friendly community:

- Clear signage;
- Good physical environment that feels safe;
- Good built environment to make mobility easier e.g. lifts, walkalators, street scapes, footpaths, gutters and curbs;
- Accessible toilets with adult change table facilities, soap to wash hands and paper towels to dry hands as hand dryers are too noisy and toilet paper dispensers that are easy to use;
- Have an area in shopping centres where you could leave your laden trolley safely when you need to go to bathroom or leave the trolley for some reason;
- Have an area where you can obtain wheelchairs close to the disabled parking bays.
- Make available stickers for businesses to indicate that they are a dementia friendly business, if eligible.
- Improved menu selections in cafes which reflects what older people want and quick service.
- More dementia training for aged care providers and hospital staff;
- More day programs and residential respite days, and less red tape in accessing them.
- Better communication between support agencies;
- Work with sporting clubs, churches and RSL's etc to encourage being dementia friendly,
- Encourage use of the ICE app or accessible emergency information on carer if something happens to carer.
- Have place at Forest Hill Chase where people with dementia could go and sit and wait for their carers to do the shopping. Somewhere quiet with tea and coffee and some supervision would be really helpful and they know they are safe;
- Have slow queues in supermarkets for people who have mobility issues or other disabilities;
- Need more support services for carers, especially to help manage difficult behaviours;
- Increase community awareness about dementia;
- Invite a local politician onto the DFC Working Group;
- Age friendly = dementia friendly.

Consultation: People Living with Dementia

A total number of 19 people aged between approx. 80 and 93 years living with dementia or some memory loss were involved in small group discussions or interviews.

Some lived alone, some with family and some lived with their spouse. Most left their home on average approximately 3 times per week to go shopping, eat out, go to the movies, concerts, visit family and friends, attend social support and/or planned activity groups and social groups, and volunteer. They also enjoyed gardening, doing crosswords, drawing, colouring in, watching TV and going for walking.

They identified that the following helps them to enjoy these activities:

- Transport- access to public and private, such as taxi's (half price taxi card);

- Support from family and friends, understanding their condition, not fussing or making too much of it;
- Responsive and respectful businesses;

However, they also identified what makes it difficult to go out and do the things they enjoy:

- Decreasing physical health;
- Difficulty with mobility such as balance, getting on and off public transport, walking and uneven and/or overgrown branches overhanging footpaths;
- Signage and finding places - signs too small;
- Places that are very busy, crowded or noisy;
- Noise and visual distractions can be overwhelming.

They also acknowledged that there were some things that they could no longer do such as, driving, house maintenance e.g. painting, climbing a ladder or walking the dog.

When asked what their impression is of how well people understand dementia the respondents said; saddened by it, a lot of people don't understand or don't want to understand.

Conclusion

The findings from the consultations provide a brief insight into the various challenges faced by people living with dementia and their carers on a daily basis. Also, are some suggested strategies that can help to alleviate or minimise these challenges.

The consultations have also highlighted a number of important actions that can be undertaken to help towards creating a more dementia friendly community, these include:

- Clearer way finding/signage;
- Accessibility to make mobility easier in the built and physical environments e.g. parking, public and private transport, access to wheelchairs, toilets and amenities and slow queues in supermarkets;
- Welcoming and safe environments without hazards and obstacles.
- Spaces that are not busy, crowded or noisy and that have adequate seating and refreshments for resting and timeout;
- Café menu selections which cater for people with dementia and older people's needs;
- Quick, responsive and respectful businesses and recognition for those businesses who are dementia friendly;
- Education-greater awareness about dementia within the local community via information on TV and radio, education in schools and at community events and presentations. More dementia training for aged care providers, hospital staff, workplaces and businesses;
- Improved access to social activities, resources and support services for people with dementia and their carers.

APPENDIX A: Consultation Participants

Community surveys

Group	No of Surveys
Senior Citizens of the Greek Community, Forest Hill	9
Greek & Cypriots Elderly Citizens Club of Whitehorse & Districts	65
Greek Elderly Citizens of Nunawading	11
Circolo Pensionati Italiani di (Blackburn North)	4
Mitcham Senior Citizens Club	7
Forest Hill Chase Shopping Centre	61
The Centre for Holistic Health	22
Umbrella Café	7
Forest Hill Village	13
Alzheimer's Australia Memory Loss event	41
Forest Hill Secondary College	3
Carrington Health	19
Brentford Square	10
Forest Hill Resource Centre	6
Unknown/Miscellaneous	33
Online	21
TOTAL	332

Interviews and group discussions

Organisation/Group	Method	Number of Participants
Uniting Age Well Strathdon Carers Group	Informal group discussion	9 carers
Uniting East Burwood Carers Group	Informal group discussion	10 people including carers, people with dementia, volunteers and staff
Uniting East Burwood Social Support Group	Informal group discussion	5 people and 2 staff
	Interviews	3 people and 1 carer
Uniting Age Well Strathdon Social Support Group for people with dementia	Informal group discussion	9 people with dementia & 2 staff
Umbrella Dementia Café	Surveys	7 individuals
Villa Maria Catholic Homes Client/Carer	Interview	1 person with dementia
Home Instead Senior Care Client/Carer	Interview	1 person with dementia
City of Whitehorse Paid Support Workers	Informal group discussion	Approximately 25 workers

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