



Dementia Expert Panel – Discussion Note

19 March 2019

How can the public and private sectors work together to create world-leading dementia-friendly communities in central London and beyond in the next five years?

To enable people with dementia, their carers, families and friends to live well with dementia, we require joined-up interventions (including, but not limited to, health, care, personal networks, commercial, community, transport).

1) Awareness Raising

- Raising community awareness is key because it both supports diagnostic rates and improves residents' day-to-day interactions (empathy, patience, good advice and information).
- Need to understand the differing needs of different communities and to tailor the approach e.g. education and breaking down stigma through working with faith/community leaders
- 22% of the UK has some level of disability. Services/buildings/transport/public spaces should be designed around this 22% so that they are accessible for all
- Consideration should be given to recruitment in public facing roles; people may be taught hard skills (driving etc.) but empathy and compassion more challenging qualities
- Good training and awareness can build empathy and compassion, enabling staff to act competently and confidently. Even limited knowledge can change people's approach and attitude.
- Experiencing life as someone with a disability can shape understanding and approach.
- There needs to be greater awareness of the different sub-types of dementia and the variances in the presenting symptoms and behavioural/health impacts.
- The dementia dialogue should start in an education setting as children can share learning at home and will take dementia awareness with them as they get older.
- People with dementia and their carers, friends and family are at risk of social isolation. Effort should be made to ensure people are aware of this aspect of living with dementia and to encourage organisations and individuals to take action to address it.
- To support social prescribing for dementia (SP), prevent loneliness and preserve resilience in the community, Arts 4 Dementia proposes to co-ordinate a volunteer creative befriender network for individuals with early symptoms of dementia, ArtsPALs (Preserve Active Life). This initiative is being launched in 2019, including presenting a paper at Arts4Dementia Social Prescribing Conference in May 2019. To find out more, please visit <https://arts4dementia.org.uk/resources/artspal/>.



2) Service Provision

- Services need to be personalised to meet the needs of the individual, including carers.
- Services should be co-produced with residents with dementia and their carers.
- It was suggested that more specialist and personalised services should be provided for BAME residents as the cultural life journey may be different and English learnt in later life might be lost through progression of dementia”.
- The needs and interests of people with young onset dementia differ from those of older people with dementia. Owing to the small number of residents with early on-set dementia, economies of scale could be achieved through working with neighbouring boroughs.
- Arts and sports play key role in quality of life. Although people with dementia might not remember the activity, they often remember how they felt.
- People with dementia need to be able to access services and feel confident in leaving their homes to see friends and family, enjoy cultural and leisure activities and go to the shops. Transport is a key enabler of continued quality of life but journey planning need to be thought through from door to door.
- Services need to be effectively advertised so that residents with dementia and their carers are aware of what is available to them.
- There is growing evidence of the importance of scents in dementia experience and service should consider means of incorporating/enhancing smells that would invoke happy memories/ones that are associated with positive experiences e.g. freshly baked bread, coffee

3) Care Planning

- Although diagnosis rates are good in Westminster and RBKC, a more holistic health and care offer should be provided to residents with a dementia diagnosis immediately post-diagnosis.
- A person-centred care plan is needed that continues throughout the dementia journey.
- Residents should ideally have a single point of contact through their dementia journey to help navigate the challenges of the system
- The timing of advanced care planning is challenging – it should be raised post-diagnosis or at the point of transitioning into a new service. However, discussing end of life care must be handled carefully and this is an area for improvement. There could be more Public Health/GP campaigns to start the dialogue prior to ill health, possibly during a post-40 GP health check.
- Co-ordinate My Care enables care planning to follow the patient

4) Utilisation of Technology

- There is growing demand for digital solutions to support people with dementia and new digital solutions are coming into the market that will enable independence, safety and wellbeing of residents with dementia and their carers.



5) Effective Design/Built Environment

- Design aids and design checklists support effective dementia-friendly design and built environment.
- A significant number of people with dementia have co-morbidities. As such, dementia design features need to be integrated into wider design requirements so that built environments/buildings are suitable for all members of the community.
- Retrospective changes - some simple adjustments can improve wayfinding for residents, lighting, signage, flooring
- Any design activity needs to be co-produced with residents.

6) Understanding and managing modifiable risk factors

- Understanding the studies and evaluating the evidence base means there is an evolving picture on dementia. Health and care professionals must stay abreast of the information.
- Already some known modifiable risk factors: smoking, high blood pressure, obesity, low levels of physical exercise, social isolation and untreated depression correlate with an increased risk of developing dementia
- These modifiable risk factors are more prevalent in more disadvantaged socio-economic groups. As such, consideration must be given to the wider challenge of tackling health inequalities.
- Incidence of dementia is falling, particularly vascular dementia through improved treatment of high blood pressure and diabetes. However, the UK's population is aging and age is a non-modifiable risk factor so the numbers with dementia are growing.
- There is emerging evidence that untreated hearing loss also increases the risk of developing dementia. UCL is conducting further research into the links between hearing loss and dementia
- Caring creates its own risk factors and carers often transition into being cared-for.

7) Best Practice Models

- Tokyo - Quiet Zones have been implemented, reducing the risk of hearing impairment (modifiable risk factor for dementia) through loud noises and also creating a more dementia-friendly environment in general
- Japan – has an aging population and has taken a number of actions to improve support for people with dementia. The dementia friends initiative started in Japan.
- Brazil – there are a number of good community support initiatives in Brazil
- Finland – the global lead for personalised services in general, not just for people with dementia
- Local Arts Services - music has a significant impact on people with dementia