<b>Item No.</b> 11.	Classification: Open	Date: 18 November 2014	Meeting Name: Cabinet	
Report title:		Dementia Friendly Southwark		
Ward(s) or groups affected:		All Wards – People living with dementia, their families and communities		
Cabinet Member:		Councillor Dora Dixon-Fyle, Adult Care, Arts and Culture		

# FOREWORD - COUNCILLOR DORA DIXON-FYLE, CABINET MEMBER FOR ADULT CARE. ARTS AND CULTURE

Due to the impact of an aging population, dementia remains one of the most significant public health challenges we face. The Department of Health already estimates that there are over 1,800 people in Southwark living with dementia. Nearly all of these people are older, although the condition can affect younger people too. Only about a half of all these people will have actually received a formal diagnosis through either their GP or the Memory Service (based at South London and Maudsley NHS Trust) There continues to be high levels of fear and ignorance amongst the wider population about dementia, at a time when the numbers of people living in Southwark with the condition is set to increase significantly.

This report is a significant step in the council's ambition to make our community dementia friendly, which in itself is part of a wider programme to deliver the Fairer Future Promise 10: the creation of an Age Friendly Borough and the establishment of a Centre of Excellence. The report authorises the council to join the newly created Dementia Action Alliance, which is an exciting partnership with the local NHS agencies, voluntary sector, commercial, sports and arts organisations, who all share a common commitment to make what they do more dementia friendly. It has the potential to improve the quality of life for many people in Southwark, either living with, or caring for, someone with dementia. The DAA could also play a wider role in supporting initiatives to ensure that there is a greater awareness of the condition within the wider community, and the steps that individuals can take in earlier life to mitigate against any future impact of dementia.

The report also commits the council to formally sign the National Dementia Declaration, which has been drafted by people living with dementia and their supporters, which itself recognises the need for the whole country to become dementia friendly. It also stresses for the need to take steps to improve the care and support for those living with dementia and recognising the need for research in the treatment and possible prevention of dementia.

I therefore ask the cabinet to approve the recommendations below.

## **RECOMMENDATIONS**

1. Agrees that Southwark becomes a Dementia Friendly borough as part of the council's wider commitment to become an Age Friendly borough.

- 2. Endorses the council joining the newly established Southwark Dementia Action Alliance, as set out in paragraphs 19-27.
- 3. Endorses the council's Dementia Action Alliance priorities for action as set out in paragraph 23.
- 4. Endorses the council signing the National Dementia Declaration as set out in Appendix 1.

## **BACKGROUND INFORMATION**

- 5. In March 2012, the Prime Minister's Challenge on Dementia was launched<sup>1</sup>. This is a programme to deliver major improvements in dementia and research by 2015 and builds on the work of the National Dementia Strategy<sup>2</sup>. Three champion groups were set up to focus on the main areas for action:
  - driving improvements in health and care
  - creating dementia friendly communities
  - improving dementia research.
- 6. A key national initiative that has been highlighted as a way of enabling dementia friendly communities is the drive to establish local Dementia Action Alliances (DAAs)<sup>3</sup>.
- 7. Local DAAs bring together regional and local organisations and bodies to improve the lives of people with dementia in their area, alongside those of their carers. DAAs are an alliance between local authorities, the NHS, community sector, public service organisations, private sector businesses, faith based organisations and arts and leisure institutions. Their collective aim being to ensure that the services that they provide and the workforce that deliver them are responsive to the needs of people living with dementia and their carers.
- 8. The type of organisation that can join the DAA is entirely flexible to what the local DAA decides. A number of DAAs outside London have for example, sought individual membership from their general population as part of their approach.
- 9. By joining the DAA, each organisation makes a commitment and signs the National Dementia Declaration. The declaration identifies seven key messages, that are phrased in the voice of a person living with dementia (as set out in Appendix 1) These are summarised below:
  - I have personal choice and control or influence over decisions about me
  - I know that services are designed around me and my needs
  - I have support that helps me live my life
  - I have the knowledge and know-how to get what I need
  - I live in an enabling and supportive environment where I feel valued and understood
  - I have a sense of belonging and of being a valued part of family, community and civic life

<sup>2</sup> Living well with dementia: a national dementia strategy (Department of Health, 2009)

<sup>&</sup>lt;sup>1</sup> https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia

<sup>&</sup>lt;sup>3</sup> <u>www.dementiaaction.org.uk</u>. In addition, the Alzheimer's Society is funded nationally by the Department of Health to promote and develop DAAs throughout the country.

- I know there is research going on which delivers a better life for me now and hope for the future.
- 10. These messages have been drawn up nationally by people with dementia and their supporters, and express their collective views of what should be heard in relation to the condition by decision makers and the wider community as a whole.
- 11. In addition each DAA member commits to carry out at least three things that their organisation or they personally will do to improve the lives of people with dementia through their work or behaviours.

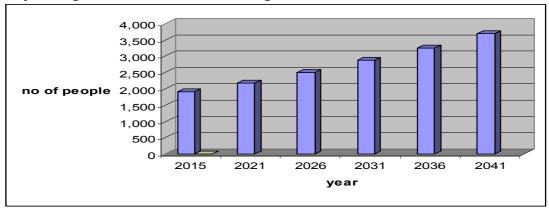
#### **KEY ISSUES FOR CONSIDERATION**

- 12. It is estimated that by 2015 there will be 850,000 people living with dementia in the UK, of which 40,000<sup>4</sup> are below pensionable age. The financial cost of dementia to the UK is estimated to be £23 billion per annum.
- 13. People living with dementia are similarly requiring increasing levels of care and support across the wider health and social care economy. It is also estimated there are 670,000 carers of people with dementia in the UK.
- 14. The Department of Health (DoH) have produced a dementia diagnostic calculating tool, which is used for planning for dementia care by Clinical Commissioning Groups (CCGs). This tool takes into account demographic and health factors to estimate the proportion of the local population that would be expected to be living with the dementia. As of March 2014 934 patients of local GPs had a formal dementia diagnosis, which according to the dementia calculator is thought to be only 50% of the total number of people who are currently living with the condition in the borough.
- 15. In 2013-14 Southwark none the less had the second highest rate of dementia diagnosis in London. The CCG aims to reach a local rate of diagnosis of 70% by the end of 2015-6. This ambition is being supported by continual improvements in dementia care and diagnosis within primary care and the memory service located at South London and the Maudsley NHS Foundation Trust.
- 16. There is a national drive to increase early diagnosis across the health and social care system. Early diagnosis can allow people with dementia the ability to make decisions whilst they still retain a degree of mental capacity, so they have a stronger prospect of retaining choice and control over their lives. It means that treatment and support can also be provided in a timely manner, which if effective can delay the onset of the most debilitating aspects of the condition and keep people independent for longer. It also allows more time for their family and carers to develop strategies and obtain any information and support that they may need.
- 17. The DoH project even further growth in the numbers of people living with dementia in Southwark in the years to come as the population ages.

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<sup>4</sup> http://www.alzheimers.org.uk/site/scripts/documents info.php?documentID=341

# Projected growth in the numbers living with dementia in Southwark<sup>5</sup>



18. Given the strong correlation between age and dementia, and the high number of older people living alone in Southwark (43%, which is higher than London and national averages) dementia is likely to continue to be a growing issue for the council, health partners and our local population in the years ahead.

#### **Southwark Dementia Action Alliance**

#### **Progress to date**

- 19. In March 2014 the council identified the benefits that establishing a DAA could bring in enabling Southwark to become a dementia-friendly community. It approached a number of local organisations who shared a similar commitment. There was a determination from the start that the DAA should seek membership beyond the traditional health and social care sector.
- 20. Since then, an increasing number of local organisations and groups have expressed interest and commitment to joining a DAA and taking action to ensure Southwark became dementia friendly. A list of agencies who have expressed a commitment to become part of the Southwark DAA is set out in Appendix 2. This list is growing and once fully launched, Southwark's DAA is set to instantly become the largest DAA in London.
- 21. As part of the desire to embed the DAA as a truly community-centered initiative a local voluntary organisation has been elected to chair the DAA Dulwich Helpline & Southwark Churches Care
- 22. Representatives from the partnership have also selected a Southwark DAA steering group, which includes representatives from the council, to ensure that the drive and momentum around local work is maintained. The steering group will meet more frequently to co-ordinate work, increase membership, promote collaboration between members and extend the scope of the DAA to further its ambition in establishing Southwark as a Dementia Friendly borough. The wider membership of the DAA will be kept up to date via a web site, as well as periodic wider membership meetings as required.

## **Priorities for action**

23. On joining the local DAA, the council will post a number of priorities for action it

<sup>&</sup>lt;sup>5</sup> Southwark Older People Joint Strategic Needs Analysis 2012

will be addressing to improve the life of people living with dementia and their carers as a step towards its Fairer Future Promise 10, to become a Age Friendly Borough. These commitments being:

- the creation of the Centre of Excellence for people living with dementia.
- the roll out of the new free assistive technology offer for anyone with a dementia diagnosis living in Southwark
- work with NHS partners, community groups and people living with dementia and their carers, to develop a clear "dementia pathway" so the people can receive the appropriate level of treatment and support throughout their journey living with the condition.
- the public library universal dementia offer, through which the library service will be more responsive to the needs of people living with dementia
- the delivery of its dementia training programme to social care staff
- work with the Dementia Friends<sup>6</sup> programme, to promote dementia friends sessions in council workplaces.
- ensure that the new housing strategy to be considered by cabinet in the current financial year addresses the needs of vulnerable people within the context of a rapidly aging population, including those who are living with complex long term conditions such as dementia.

#### **Next steps**

- 24. In order to be part of the wider DAA movement, key next steps involve signing up to the National Dementia Declaration and publishing the action plan on the Southwark DAA web site, that sets out how the local alliance is delivering outcomes outlined in the declaration.
- 25. The aim is for the local DAA to build upon the positive momentum created thus far, to be a community based initiative that will develop organically in response to the needs of the population living with dementia and their carers and supporters.
- 26. A Southwark DDA web page was set up by the Alzheimer's Society<sup>7</sup>, to enable members to post their action plans and as a means of communication on progress of the DAA or other related news
- 27. The DAA will also work in close partnership with the national Dementia Friends programme. This community based initiative has a target to identify 1,000,000 "Dementia Friends" in the UK. Under this initiative, trained volunteers provide one hour fun filled information sessions for people in their work place, faith based venue or any other community setting, that aim to provide basic information on dementia and ask for individuals to commit to three basic things that they will personally do to improve the lives of people living with dementia. This programme is a powerful tool in order to achieve a wider community ownership of the shared challenge posed by dementia as a result of a rapidly aging population.

#### **Policy implications**

28. This work forms part of a wider programme to implement the Fairer Future Promise 10, to make Southwark an Age Friendly Borough and the creation of a Centre of Excellence for People Living with Dementia. This will be further

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<sup>&</sup>lt;sup>6</sup> https://www.dementiafriends.org.uk/

<sup>&</sup>lt;sup>7</sup> http://www.dementiaaction.org.uk/local alliances/8628 southwark dementia action alliance

considered by the cabinet in the new year.

- 29. Involvement in the DAA is a further way of cementing the council's commitment to effectively support people with dementia and their carers in a number of other local initiatives and policy initiatives, such as:
  - extension of the council's free telecare offer to individuals with a diagnosis of dementia
  - implementation of our wider carers' strategy to improve outcomes for all carers
  - leading work on integrated working with the Clinical Commissioning Group (CCG) and through the Southwark Lambeth Integrated Care (SLIC) programme, which includes a work stream focusing on dementia and the development of an improved "Dementia Pathway" in Southwark.

## **Community impact statement**

- 30. Dementia is associated primarily with aging, and it is calculated that one in three people nationally<sup>8</sup> over the age of 65 will develop dementia at some stage, with rates increasing the older people become. For example, the proportion of people with dementia doubles for every five-year age group over 65. The local situation would appear to mirror these national trends. The memory service hosted by SLAM<sup>9</sup> reported last year, 75% of all diagnosis was amongst people aged over 80.
- 31. Nationally 4.7% of people living with dementia are estimated to be below 65. People living with a learning disability are more likely to develop dementia earlier than the general population, but diagnosis often goes unrecorded as they do not attend mainstream NHS dementia services. The memory service in Southwark only diagnosed one person in the last 12 months who was under 65. The council will consider what are the drivers for this, and what this means in relation to a dementia friendly borough as part of its ongoing work with its NHS and community partners.
- 32. It is further estimated that nationally two thirds of all people living with dementia are women, which is consistent with a general longer life expectancy amongst women compared to men. Women are also often more likely to be the carers of people living with dementia. However in Southwark recent rates of diagnosis at the memory service amongst men (41%) appear higher than national averages. The council will consider what are the drivers for this, and what this means in relation to a dementia friendly borough as part of its ongoing work with its NHS and community partners.
- 33. An Equality Impact Assessment (EIA) carried out in 2012 of users of the council's in house day services as part of the consultation process on the Centre of Excellence, also found a higher rate of men living with diagnosis accessing these services than might be expected, considering national averages.
- 34. The All Parliamentary Group on Dementia enquiry 2013<sup>10</sup> concluded that evidence in relation to ethnicity and dementia was limited. It did however indicate there might be lower awareness, higher levels of stigma, and different cultural

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<sup>8</sup> http://www.alzheimers.org.uk/site/scripts/documents\_info.php?documentID=341

<sup>&</sup>lt;sup>9</sup> Southwark Clinical Commissioning Group Data

<sup>10</sup> http://www.alzheimers.org.uk/site/scripts/documents info.php?documentID=1583&pageNumber=2

understanding of dementia among people from some Black, Asian and Minority Ethnic (BAME) communities. Language and cultural differences may result in people presenting later to general dementia services than their white British counterparts.

- 35. Locally the evidence in relation to ethnicity and dementia is also limited. The memory service report that rates of recent diagnosis amongst BAME communities is around 27% of all people diagnosed. This being higher than the 19% of the total older population who are from BAME communities recorded in the 2011 census. The largest groups being from the Afro Caribbean and African communities, corresponding with the wider demographic make up of the borough.
- 36. The council EIA referred to above also concluded that almost 33% of users of in house dementia day services were from BAME communities. Again the council will work with NHS partners in the future to ensure that dementia services are responsive to the needs of an ethnically diverse service user population.
- 37. By the nature of their condition, people living with dementia would also be considered under the equality duty as being disabled. However as the condition disproportionately affects the very old, or people living with a learning disability, people with dementia are also likely have one or multiple other long term conditions or disabilities as well as dementia.
- 38. The data available in relation to correlation of the prevalence of dementia and marriage/civil partnership, sexuality, gender reassignment and faith is very limited. However given the inclusive nature and objectives of the DAA it is believed that its establishment in Southwark will improve the quality of life of these groups, in situations where they are impacted by dementia.
- 39. Therefore with regard to the council's duties under section 149 of the Equality Act, it is of the opinion that the creation of a DAA as a step towards the creation of a Dementia and Age Friendly borough will have a positive impact upon the groups listed under the council's equality scheme.

#### **Resource implications**

- 40. The council's staffing resources deployed to develop the local DAA have been contained within existing Children and Adults Commissioning Department structure. Similarly ongoing participation in the steering group will also be met from existing staffing resources.
- 41. Any staff training will developed through the general staff training and development programme.

#### Legal implications

42. Please see the legal concurrent below.

#### **Financial implications**

- 43. There are no particular finance implications to consider as a result of this report.
- 44. Through the initial preparatory work of the partners involved in the creation of the Southwark DAA, an opportunity has been identified for funding for infrastructure

costs from a local health related grant giving body. This is now being actively pursued by the DAA steering group. If secured, this funding will be used to employ a worker to be located with one of the DAAs voluntary sector partners, to provide a resource on the ground to expand the scope and scale of the DAA within the community.

#### Consultation

45. The council has sought the views of partners on its intention to develop a DAA in Southwark. This has included consultation through the Older People Partnership Board and the SLIC Dementia work stream. This consultation has included discussions with older people representatives as well as statutory and community sector partners in this field.

#### SUPPLEMENTARY ADVICE FROM OTHER OFFICERS

#### **Director of Legal Services**

46. The report sets out what is involved in becoming a member of the Southwark Dementia Action Alliance and explains how those commitments are already aligned to much of the work the council has or is planning to undertake. It is noted that the Centre of Excellence for People Living with Dementia will be considered in a further report to Cabinet in the New Year. There are no other legal implications arising from the recommendations being made in this report

# Strategic Director of Finance and Corporate Services (FC14/026)

- 47. The strategic director of finance and corporate services notes the recommendations in this report relating to Southwark becoming a Dementia Friendly borough as part of the council's wider commitment to become an Age Friendly borough.
- 48. Staffing resources to develop the DAA will be contained within existing budgets.
- 49. The report identifies that officers are pursing funding for infrastructure costs from a local health related grant giving body.

#### **BACKGROUND DOCUMENTS**

Background Papers	Held At	Contact				
Equality Impact Assessment for the Centre of Excellence	Southwark Council, 160 Tooley Street, London SE1 2QH	Andy Loxton ext 53130				
Link: <a href="http://moderngov.southwark.gov.uk/ieListDocuments.aspx?Cld=302&amp;Mld=4864&amp;Ver=4">http://moderngov.southwark.gov.uk/ieListDocuments.aspx?Cld=302&amp;Mld=4864&amp;Ver=4</a>						
Draft Terms of Reference for the	Southwark Council,	Andy Loxton				
Southwark Dementia Action Alliance	160 Tooley Street, London SE1 2QH	ext 53130				
Link: http://moderngov.southwark.gov.uk/ieLi	ietDocuments aspv2Cld=303	28 MId=49648 Vor=4				

# **APPENDICES**

No.	Title		
Appendix 1	National Dementia Declaration		
Appendix 2	List of organisations who have committed to join the Southwark		
	Dementia Action Alliance in December 2014		

# **AUDIT TRAIL**

<b>Cabinet Member</b>	Councillor Dora Dixon-Fyle Adult Care, Arts and Culture					
Lead Officer	Jay Stickland, Director of Adult Social Care					
Report Author	Andy Loxton, Commissioning Manager					
Version	Final					
Dated	6 November 2014					
Key Decision?	Yes					
CONSULTATION WITH OTHER OFFICERS / DIRECTORATES / CABINET						
MEMBER						
Officer Title		Comments Sought	Comments Included			
Director of Legal Services		Yes	Yes			
Strategic Director of Finance		Yes	Yes			
and Corporate Serv	vices					
Chief Executive's Department		Yes	Yes			
Environment and Leisure		Yes	Yes			
Cabinet Member		Yes	Yes			
Date final report sent to Constitutional Team 6 November 2014			6 November 2014			